"It's my body, I can have a say"

The development of a theory and evidence-based intervention to prepare and support adolescents with long-term conditions to participate in shared decision-making

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List of abbreviations

HCP: Healthcare professional

HIV: Human immunodeficiency virus

IMP: Children's Health Information Matters Project

IMA: Intervention Mapping Approach

LTC: Long-term condition

MRC: Medical Research Council

NHS: National Health Service

NICE: National Institute for Health and Care Excellence

NIHR: National Institute for Health Research

NETSCC: NIHR Evaluation, Trials and Studies Coordinating Centre

PREECEDE: Predisposing, Reinforcing and Enabling Constructs in Educational Diagnosis and Evaluation

RCT: Randomised controlled trial

SDM: Shared decision-making

TDF: Theoretical Domains Framework

UN: United Nations

WHO: World Health Organisation

Summary

Adolescents with long-term conditions (LTCs) often adopt a marginal role during healthcare consultations, which does not reflect their role in condition self-management. Shared decision-making (SDM) gives adolescents a voice in their healthcare and treatment plans, improving the likelihood of selecting the best possible option for them. Literature in this area is limited, and much of the research to date has focused primarily on the views of parents and clinicians, with little attention to the adolescents' perspectives. The work in this thesis describes the development and user-testing of an intervention informed by adolescents and relevant theory, which aims to prepare and support adolescents with LTCs to participate in SDM.

Development and user-testing was guided by the MRC's framework for developing complex interventions and the Person-Based Approach. A systematic review revealed that preferences of adolescents with LTCs around involvement in decision-making can vary substantially, but often go unmet. Reasons for the discrepancy between adolescents' preferences and experiences were further explored in qualitative participatory interviews, and perceived barriers to, and facilitators for SDM were identified.

The Intervention Mapping Approach was used to develop a theory and evidence-based intervention in the form of a 12-page booklet titled "*It's my body, I can have a say*" which aimed to address the identified barriers. User-testing with adolescents with LTCs and clinicians revealed positive responses to the booklet's key messages and design. Suggested changes were made to improve acceptability of the booklet, which included the addition of a short video and electronic format. Design for further feasibility testing was proposed.

Overall, preliminary findings suggest that the intervention could be a useful tool for preparing and supporting adolescents with LTCs to be involved in SDM, and for addressing the perceived barriers to involvement. However, preparation for SDM must be paired with willing and skilled clinicians, supported by parents, and delivered within a supportive environment.

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Chapter 1: Introduction and thesis overview

1.1 Chapter overview

This PhD aims to achieve an in-depth understanding of adolescents with long-term conditions' (LTCs) perceptions of barriers to, and facilitators for shared decision-making (SDM) about their healthcare in order to develop an intervention to prepare and support adolescents with LTCs to be involved in SDM with their healthcare professionals (HCPs). This introductory chapter aims to provide an overview of the context and challenges around healthcare decision-making with adolescents with LTCs. The need for an intervention that prepares and supports adolescent involvement in SDM will be highlighted, followed by a description of the aims, objectives, and the rationale of the PhD. Finally, an outline of the PhD chapters including research objectives, phases, and methods will be presented.

1.2 Clinical background

1.2.1 Long-term conditions in adolescence

A LTC is defined as a condition which cannot at present be cured, but can be managed by a combination of medications, therapies and behavioural healthcare regimens such as diet and exercise (1). Asthma, Type 1 diabetes, epilepsy, and inflammatory bowel disease are examples of LTCs prevalent in paediatric patients. Some children develop LTCs early in life often persisting into adulthood, while certain LTCs tend to develop during adolescence (2). For example, young people aged 16 to 20 are the group most likely to be diagnosed with asthma, and age 11 to 14 is the peak age for diagnosis of Type1 diabetes (3).

The prevalence of LTCs among adolescents is difficult to assess due to the lack of quality data focusing specifically on this age group, as well as the diversity in methodology and definitions used (4-6). The largest epidemiological study to date on the prevalence of LTCs in childhood states "*an estimated 31% of children under 18 years of age, were reported to have one or more chronic condition*"(2). More recent research in Wales found that 19% of adolescents in school years 7 to 11 (generally aged 11 to 16) reported having a LTC diagnosed by a HCP, with no difference between genders (7). Twenty percent of the UK population fall into the category of adolescence, which is defined as between the ages of 10 and 19 (8). It can therefore

be estimated that there are around three to four million adolescents living with LTCs in the UK today.

Adolescence is a key period for establishing lifelong health behaviours, and a time often related to a decline of positive health behaviours, such as physical activity and nutritious eating habits (7, 9). Adolescence, which is marked by physical, psychological, and social changes, is also associated the emergence of risk factors which can have consequences for adolescents' health related quality of life, and overall wellbeing (10-12). Adolescents with LTCs have been found to be significantly more likely to engage in risk-taking and experimental behaviour, such as alcohol and drug use, when compared to their peers who did not report a LTC (13, 14). It is therefore crucial for the clinical teams working with adolescents with LTCs to be aware of these potential risks in order to provide the necessary support, as the effects are likely to be even more harmful to those already living with health issues. It is also essential for adolescents with LTCs to adopt healthy behaviours, initiating effective condition management as soon as possible post diagnosis in order to maintain the habits into adulthood.

It has been suggested that although there are issues specific to each condition, there are many commonalities experienced across all LTCs (15). Adolescents living with different LTCs report experiences of common stressors and challenges which can have a significant impact on their lives, including feeling set apart from others and feelings of isolation due to exclusion by peers; restrictions and loss of autonomy; issues related to treatment and self-management, including feeling burdened; and the importance of support from family and friends and coping strategies (16-20). On average, 38% of adolescents with various LTCs living in Wales say their LTC impacts their attendance and participation in school, which increases as they grow older (7). Adolescents with LTCs have been found to have poorer educational, vocational and financial outcomes in young adulthood, when compared to their peers who did not report LTCs (21). It is therefore crucial that adolescents with LTCs are receiving sufficient support to help cope with and manage their condition so that it has minimal impact on their lives in order for them to be able to strive both academically and socially.

1.2.2 Condition management of adolescents with long-term conditions

Adolescence is a critical period of psychosocial development in which young people experience a change in interpersonal roles, responsibilities, and identity (22, 23). Unsurprisingly, these years can be more complex for those living with a LTC, as they have to balance the usual tasks of adolescence with the adaptive tasks presented by their LTC. Such adaptive tasks include managing symptoms and treatment; forming relationships with clinical team members; managing emotions; maintaining a positive self-image; relating to family members and friends; and preparing for an uncertain future (24). Balancing these tasks is complex, as a LTC and its treatment can have a significant impact on different areas of daily life. Living with epilepsy, for example, is characterised by concerns of disclosure being met with negative reactions from peers; the uncertainty around seizure occurrence; and experiencing side-effects from antiepileptic medications, such as drowsiness and changes in mood (16).

LTC management is an important issue in paediatric healthcare given the intensive regimes, and potential for future complications if not done effectively. For example, type 1 diabetes involves a lifetime of monotonous and rigorous healthcare management often including daily monitoring of glucose levels and insulin injections, which can encroach on academic achievement and personal aspirations (25). If glucose levels are not effectively managed, complications can include heart and kidney problems, nerve damage and stroke (26). Although younger children usually rely on parents to take responsibility for their condition management, adolescents identify taking ownership of their condition as an integral component of successful self-management (27). Adolescents with LTCs increasingly take on healthcare management responsibility from their parents, sometimes doing the majority of self-care tasks by the age of 13 (28-32). However, self-management and health outcomes of patients with LTCs often decline during adolescence, which can lead to increased likelihood of health complications and hospital admissions (32-34). Key barriers to condition management reported by adolescents include attitudes, self-efficacy, and life disruption (35). A self-management regimen which does not allow adolescents to meet their social needs can cause resentment and also decreases the likelihood of maintaining self-management behaviours (36).

This emphasises the importance of adolescents' involvement in their healthcare decision-making, as adolescents are the experts in their own social needs.

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Adolescents with LTC express the desire to have more control in their lives by being more involved in making decisions about their condition management (36). They also highlight the importance of learning about their condition in order to maintain a sense of control (27). This can enable the selection of healthcare options which best aligns with adolescents' capabilities, needs, preferences, and values.

1.2.2.1 Parental role and support in condition management

As mentioned in the precious section, transitioning from childhood to adolescence involves a role shift for parents and adolescents with LTCs, where parents are expected to move from assuming responsibility for their child's healthcare needs to helping them to develop self-management skills (37). For younger children, parents are expected to take charge of condition management, completing, or assisting with the self-management tasks (38). To do so, parents need to gain in depth knowledge of their child's condition and available healthcare options, learn how to identify and respond to their child's symptoms and develop effective relationships with HCPs (38-41). This care-giving and support above the usual parental tasks are pivotal for children with LTCs but often leaves parents with minimal time for addressing their own needs (42).

The parental role in adolescent self-management can either be hindering or facilitating of adolescents' independence and development of self-management skills (43). As children become adolescents, they are expected to gradually take over self-management tasks, while parents should support this acquisition of autonomy and cede control (44-46). Parents begin to support their child's self-management ownership by encouraging them to "know" their own bodies to be able to articulate symptoms to others and decide on any actions needed, then over time providing opportunities for their child to become involved in aspects of managing their condition and in taking increasing control in decision-making (43). Even after responsibilities have been transferred, parents continue to play a surveillance role, monitoring their child's health and self-management, and providing reminders when necessary (43). The quality of parental surveillance and the parent-adolescent relationship are important for adolescent self-efficacy around self-management, and have been linked to improved healthcare adherence and health outcomes (47).

However, parents are often less convinced of their child's condition management capabilities than adolescents themselves, and may be wary about providing more room for independence (48). This could be due to parental overprotection, which often stems from parents' perception of their child as vulnerable because of their LTC or concerns over health complications as a result of their taking responsibility for their condition (49, 50). As a consequence, adolescents can feel restricted from gaining more autonomy and condition ownership and responsibility (48). Research has shown that parents need support with the process of transferring condition responsibility to the adolescent and "letting go" (46, 48, 49, 51). This includes supporting and encouraging their involvement in healthcare decision-making.

1.3 Adolescents' decision-making in healthcare

Recommendations state that adolescents should have access to information regarding their health and be involved in healthcare decisions. The list of bodies, organisations and policy documents that support the involvement of adolescents with LTCs in decision-making about their healthcare is extensive. Among a few: the British Medical Association states that "*Doctors should aim to involve all children and young people in decisions relating to their medical treatment*" (52); the United Nations (UN) General Assembly on Children outlines the importance of respecting the views of children and their involvement in health decisions (53); the Children Society's 'Good Childhood Report' advocates that it is crucial for young people to be able to exercise choice over their lives for their personal wellbeing (54); the World Health Organization (WHO) emphasises the importance of taking on the wishes, desires, knowledge base, capabilities and rights of adolescents with LTCs in the delivery of health services, albeit also acknowledging that these wishes, desires, knowledge, capabilities and rights are constantly evolving and changing (5); finally, the UN Convention on the Rights of the Child states that "*every child has the right to the best possible health*" and that "*every child must be free to express their thoughts and opinions and to access all kinds of information*" (55). Therefore, adolescents with LTCs not only have the right to have access to the most effective and most appropriate healthcare delivery, but also the right to have access to the information around their health condition and healthcare options, as well as the involvement in the decision-making process.

In the United Kingdom, adolescents over 16 years are legally entitled to consent to their own treatment and healthcare, as they are presumed to have sufficient capacity to decide, unless there is significant evidence to suggest otherwise (52, 56). However, it is recommended that HCPs do not judge a child's ability to make a decision solely on the basis of their age, and that those under the age of 16 can make decisions about their treatment if deemed to have enough intelligence, competence and understanding to fully appreciate what is involved, also known as being "Gillick competent" (52, 57, 58). To be deemed competent, those under 16 should want to make, and be able to understand there is a choice; that choices have consequences and be able to weigh the information to arrive at a decision; understand the nature of the proposed treatment, potential side-effects, and the risks of alternatives; and be free from undue pressure (52, 59). From a neurological development perspective, Grootens-Wiegers and colleagues concluded that at the age of twelve adolescents generally have the capacity to be competent to make decisions about their healthcare (60). Legally, if a child is deemed competent and wishes to receive treatment, parents cannot override their decision, however, unlike adults, if under-18s refuse treatment which is seen to be in their best interest, it may be overridden by their parents or the Court (58, 59).

1.3.1 Adolescents' capacity for decision-making

Behavioural decision theory states that all behaviours can be analysed as the outcome of the decision-making process which involves: identifying the options, identifying consequences which follow each choice, and evaluating the desirability and the likelihood of each consequence (61). All this information is combined and deliberated upon to reach the decision. Although this model, which may not account for instinctive or habitual behaviour, might be viewed as somewhat simplistic, it is useful to gain insight into the use of abstract reasoning in decision-making to anticipate and evaluate possible outcomes.

Adolescents' capacity for abstract reasoning is critical for their evaluation of the risks and benefits of healthcare options, as healthcare decision-making requires the ability to understand information without experience, and reason about hypothetical probabilities (e.g. side-effects); weigh and prioritise abstract factors taking a future time perspective; and engage in inductive and deductive reasoning (62). Adolescents of the same age can vary considerably in these abilities, which may

depend on their cognitive and social development as well as previous experiences, including experience with responsibility for decisions (60, 62). The reward system of the adolescent brain, in its complex developmental state, has been suggested to be responsible for the tendency to focus on the more immediate benefits, ignoring long-term consequences thus often engaging in more risk-taking behaviour as mentioned previously (63). However, this is not necessarily reflective of adolescents' ability to deliberate and engage in decision-making processes, as perceptions of what constitutes risk can be subjective, and adolescents may give more consideration to certain risks (e.g. social consequences) than others (e.g. health risks) (64, 65).

A review of studies examining adolescent decision-making processes found that most studies reported adolescents use similar processes when making a decision to adults (65). Furthermore, although a difference between children and adolescents in information processing was identified, there was very little difference between adolescents and adults (66). As touched on previously, adolescents and adults may come to different decisions due to differences in values around identification of, and perceptions of, likelihood of possible consequences (65). For example, adolescents may decide differently from adults by choosing a healthcare option which they deem to be more socially acceptable or most beneficial in the short-term, which may in fact be the best option for the individual as it aligns with what is most important to them, thus perhaps making the option easier for the adolescent to adhere to.

The ability of adolescents with LTCs to make informed and thoughtful decisions about their healthcare has been documented (67, 68). Moreover, patient involvement in decision-making has been identified as a key indicator of adolescent healthcare quality (69). The arguments for adolescents with LTCs making healthcare decisions are robust, however, patients may need support with this process to enable effective consideration of long-term consequences. It is important to ensure that adolescents with LTCs are aware of the risks relating to the different options, as well as the likelihood of said risks occurring, in order for the deliberation process to be most effective.

1.3.2 Decisional conflict

When involved in decision-making, adolescents with LTCs may face difficult healthcare decisions, which can lead to decisional conflict (70, 71). Decisional

conflict is defined as a state of uncertainty about which course of action to take when deciding between two or more options that involve risk, loss, potential for future regret, or challenges to personal life values (72, 73). Much of the research on decisional conflict in paediatrics has focused on measuring parents' experiences (74-81). However, the Decisional Conflict Scale, which is the most widely used tool that measures decisional conflict, was able to be understood and effectively completed by adolescents with LTCs (73, 82).

For many adolescents with LTCs, healthcare decisions may be 'preference-sensitive', based on the individual patient's personal values, preferences and self-efficacy, meaning options often require deliberation (83, 84). These types of decisions may invoke decisional conflict, particularly when the likelihood of expected outcomes is not definite (73). Decisional conflict may be particularly prevalent for adolescents with LTCs when deciding on options which cannot be reversed, such as renal transplantation (70, 85-87). However, levels of decisional conflict were reduced when adolescents with LTCs information needs were met, including more awareness and knowledge of risks (88).

1.4 Shared decision-making with adult populations

Over the past two decades, healthcare delivery in the UK has shifted focus from paternalistic decision-making, whereby HCPs make decisions in patients' perceived best interests, to SDM, wherein both patients and HCPs play active roles, exchanging information and reaching consensus based on current healthcare evidence and patients' preferences (89-93). Sharing decisions between HCPs and patients involves a shift in power from the traditional paternalistic care, thus recognising patient autonomy, and has increasingly become patients' preferred role in decision-making (94, 95).

SDM is a dynamic and complex process in which HCPs and patients work together, putting the patients at the centre of decision about their own healthcare (96). It is a collaborative approach to care which recognises that both HCPs and patients contribute two different but complementary forms of expertise to the process (90). HCPs' expertise includes diagnosis, disease aetiology, prognosis, treatment options and outcome probabilities; whereas patients' expertise includes their experience of illness, social circumstances, attitudes towards risk, values, and preferences (97). It

is important to note that SDM is not simply providing the patient with information and leaving the decision-making to the individual, but a partnership where the HCP helps the patient to choose from a range of appropriate options, including sometimes doing nothing, by informing and encouraging patients to share their personal preferences and based on what is important to the patient (90, 98).

A systematic review of articles containing SDM definitions conducted by Makoul and Clayman resulted in the development of an integrated model of SDM (Table 1). The review identified essential SDM elements including; defining the health problem and presenting options, discussing the benefits and risks of each option, eliciting patient values and preferences, clarifying patient understanding, discussing patient self-efficacy around options, making recommendations, then making or explicitly deferring a decision (99).

Table 1. Adapted from Makoul and Clayman's (99) Integrative Model of Shared Decision-making in Medical Encounters

Essential Elements	Ideal Elements	General Conceptual Qualities
Define/explain the health issue	Unbiased information	Deliberation/negotiation
Present options	Define roles (assess patient desire for involvement)	Flexibility/individual approach
Discuss risks/benefits of the options	Present evidence	Involves at least two people
Discuss patient ability/self-efficacy	Mutual agreement	Middle ground (between paternalism and informed choice)
Check and clarify understanding		Mutual respect
HCP contributes knowledge/recommendations		Partnership
Decision discussed		Patient participation
Arrange follow-up		Process/stages

Elwyn and colleagues' three-talk model for SDM includes three key steps where HCPs support deliberation through the process, namely: *team talk* (previously called *choice talk*)*, option talk* and *decision talk* (Figure 1) (98, 100)*. Team talk* is about introducing the concept of the patient and HCPs working together as a team, making patients aware of options, and eliciting patient goal. The concept of working as a team or partnership may be of particular importance to adolescents with LTCs, who tend to have regular consultations with the same clinical teams, but are often left out of the conversation (101, 102). *Option talk* involves discussing the available healthcare options, along with the risks and benefits of each, often accompanied by

patient decision support (e.g., decision aids). *Decision talk* focuses on patient values and preferences and moving towards a decision.

SDM has been widely researched in adult populations but due to low certainty of evidence, the degree to which it may benefit patients remains unknown (103, 104). However, a systematic review that examined the impact of SDM between HCPs and adult patients showed some statistically significant and positive associations between SDM and affective-cognitive outcomes (e.g. knowledge, understanding and trust), behavioural outcomes (e.g. medication adherence and health behaviours), and health outcomes (e.g. reduction in symptoms, quality of life and psychological measures) (104). Furthermore, SDM is a key element of patient-centred care and has been defined as an '*ethical imperative'*, resting on the principles of good clinical practice (105, 106)*.* SDM is recommended by all National Institute for Health and Care Excellence (NICE) guidance, and stated by NICE quality standards to be an essential component of good quality care, with SDM guidance due to be published in 2021 (90).
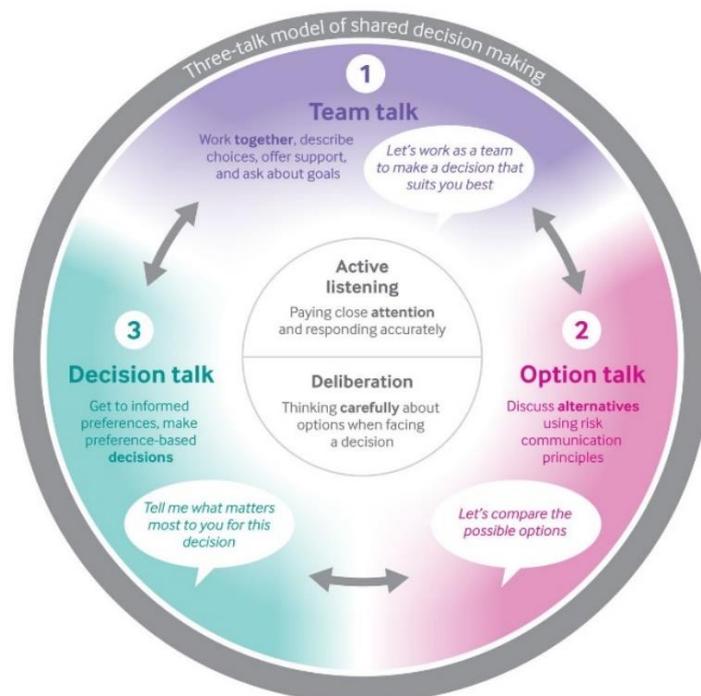
Figure 1. Three-talk model of shared decision-making (100)

Both models described in this section were developed for adult patient populations. Paediatric SDM is more complex due to the nature of the patients and the inclusion

of parents. The complex dynamic of the triadic relationship present in paediatric care is explored in more depth below.

1.4.1 Patient decision aids

Patient decision aids are patient-friendly tools to support healthcare decision-making, thus improving the quality of decisions and care provision (107-109). These tools are used to make the proposed decision explicit, provide evidence-based information about the options and outcomes relating to the decision, and help clarify patients' values relating to the options (107-109). There is a growing interest in the use and development of decision aids globally, however researchers have been concerned about their quality and effectiveness. In 2003, a group of researchers, stakeholders and practitioners from around the world formed the International Patient Decision Aid Standards Collaboration to enhance the quality and effectiveness of patient decision aids based on evidence (110). The group developed an instrument to evaluate patient decision aids, consisting of checklist to assess the development process, information provision, values clarification, and effectiveness (109-111). Currently, The Ottawa Hospital Inventory of patient decision aids includes over 300 publicly available decision aids that meet a minimum set of criteria, which support numerous clinical decisions, including options for screening testing, undergoing surgery or commencing a medical regimen (112). Benefits of decision aids compared to usual care include increased patient knowledge, accuracy of risk perceptions, congruency between informed values and care choices; and reduced decisional conflict (113).

Nonetheless, decision aids may not always be available when a healthcare decision needs to be made. Although there are many decision aids to support parents with decisions about their child's healthcare, there currently exist very few decision aids targeted at child and adolescent patients (112-121). Furthermore, with an inexhaustible number of possible decisions across all healthcare areas, it would be near impossible to have a decision aid for every circumstance. Decision aids are useful tools which can support the SDM process by providing patients with information about options and supporting the patient to compare the options in relation to their personal values. However, decision aids do not equal, or necessarily achieve, SDM. It is possible for SDM to take place without the tool, but not without the necessary skills of HCPs or patient willingness.

1.5 Shared decision-making with adolescents with long-term conditions

The UN Convention on the Rights of the Child (55) and The Children Act (122) both highlight the importance of health professionals taking a more child-centred approach within their practice. Current recommendations state that adolescents should be encouraged and supported to participate in healthcare decisions, and that health service provision should be a partnership between the HCPs, young persons and their families (55, 123). With continual development of medical technology for paediatric healthcare, and challenging decisions faced due to trade-offs between the risks and benefits of multiple options, there is a growing need to understand the concept of SDM in the paediatric field (124, 125).

Decision-making around LTC healthcare can be a continual process, with no clear beginning or end; where numerous decisions are taken, evaluated and often revaluated (126). Montori and colleagues emphasise the need for patients to take a more active role in treatment decision-making in a chronic care setting, which offers a longer window of opportunity to make decisions, and to revisit and perhaps reverse decisions without important loss; compared to patients in acute care settings where decisions are often urgent and may be irreversible (127). SDM is particularly relevant for 'preference-sensitive' decisions which are often characteristic of chronic healthcare decision-making (83, 84). An example includes the options of injecting versus a pump to administer insulin to manage Type 1 diabetes, where the best option often depends on the individual's preferences and capabilities.

When compared to adult healthcare, SDM with adolescents usually has the additional dynamic of parental involvement in the discussions and decision-making, often referred to as a "triadic relationship", which is not a straightforward matter to accomplish (128). In some cases parents' preferences may overrule those of the adolescents, whereas in others the adolescents' choice may overrule that of their parents, thus making SDM different and more complicated than in adult care (129, 130). Collaborative and active participation of parents, patients, and HCPs to achieve a common goal are key attributes of the triadic relationship for SDM in paediatrics (128, 131). This can be particularly difficult in adolescence as the child-parent relationship develops and children begin to gain independence from their parents, with differing perspectives and priorities. Parents may struggle with the contradictory roles of needing to protect their vulnerable child and to promote

autonomy and the development of their own separate identities (132). Parental involvement in the form of a high quality parent– adolescent relationship, including love, acceptance and appreciation of the adolescent; communication frequency and independence encouragement is important for the health outcomes of adolescents with LTCs (47).

The three talk (100) and integrative (99) models of SDM described above have been created and widely utilised for SDM with adult patients, and to date SDM in paediatric healthcare has been described as poorly defined as it has been used interchangeably with similar terms in research, such as joint decision-making, and not widely implemented in clinical practice (125, 131, 133). As Gabe and colleagues (128) state: "*In any encounter involving three or more actors there is a tendency for two of them to enter a coalition in order to advance a personal agenda or achieve an agreed outcome*". For example, parents' desire to see improvement to their child's LTC symptoms may result in a coalition between the doctor and parent to pursue a given treatment despite the adolescent's preferences (128). On the other hand, a coalition between HCP and adolescent could help the adolescent with a LTC to advocate their preferences and resist pressure from parents to make a hasty decision or conform to the parent's choice. Developing a three-way partnership in adolescent healthcare involves altering the power imbalance which has traditionally characterised medicine as well as the relationship between parent and child (128). In the situation where the adolescent takes a large share of the responsibility over their condition management, it is crucial that they are included in healthcare discussions and decision-making and on board with the selected option.

SDM provides the opportunity for patients with LTCs to evaluate the risks, benefits and costs of various management options and procedures for their condition, while enabling a shared understanding of preferences and possible issues, such as difficulties with side-effects or in performing self-management tasks (99). This may be particularly relevant for an adolescent population, where minimising disruption to daily life is a key facilitator to engaging in condition management tasks (35). SDM may increase adherence to self-management plans (134-136), which can be particularly important during adolescence when self-management and health outcomes of patients with LTCs have been found to decline (33, 34, 137). In addition, adolescent involvement in healthcare decisions is associated with a better

understanding of their health condition and treatment (138-140), and there is some evidence to suggest that SDM in paediatric chronic healthcare may be associated with decreased hospital visits and medical expenditures (141).

However, despite legislation, policies, and support for SDM in paediatric medicine, research evidence consistently shows that young people are insufficiently involved in health decision-making, despite often wanting a more participatory role (142-144). SDM does not routinely occur in clinical encounters, and adolescents with LTCs often act as bystanders (101, 102). Furthermore, previous research in decision-making in paediatrics has predominantly focused on interactions between the parent and HCPs, omitting the adolescent voice (114, 145, 146). Due to the complex triadic relationship, parent involvement can prevent SDM from occurring between the young patient and HCP (147).

A review (143), which identified literature addressing adolescents', parents' and HCPs' experiences of decision-making in paediatrics, found that adolescents' views in health consultations were rarely sought or acknowledged. Nonetheless, most of the studies in the review did not actually explore the patients' perspectives (143). This is reflective of the exchange during a paediatric consultation, where adolescents' voices are rarely heard, and they tend to act as bystanders (101, 148). For example, observational research revealed that asking for adolescents' input about their asthma management during clinical encounters was infrequent, occurring in only 6% of visits (149).

Authors have called for more research exploring the role played by young people living with LTCs during clinical encounters, particularly from the patients' perspectives (142, 143, 150). There have also been calls for more interventions to support young people's engagement and inclusion in SDM (115, 151-153). Systematic reviews which aimed to examine the effects of SDM interventions for young people with cancer and cystic fibrosis retrieved no results (115, 116). There is a need for more investigation around, and support for the involvement of adolescents with LTCs in SDM. This would enable open communication and information sharing around options, as well as around the adolescent's own values, preferences, behaviour, self-efficacy, and wellbeing in order for effective and collaborative decision-making to take place, and for necessary support to be provided.

1.5.1 Parent's roles in paediatric SDM

Parents of adolescents with LTCs assume a wide range of roles during clinical encounters. These can include the role of advocate for their child; experts about their child's condition and quality of life; and protectors of their child as well as the family identity and values (154). Adolescents with LTCs generally appreciate and accept their parents' involvement in decision-making about their healthcare, particularly when they feel too overwhelmed or unwell to participate, and trust them to make decisions on their behalf (154, 155). Adolescents often report their views to their parents, who in turn may act as their voice, representing the adolescent in healthcare decision-making and looking out for their best interests (154, 155). Even older adolescents rely on parental support in clinical decision-making, often turning to them for advice (155). Adolescents' relationships with their parents are important in SDM processes. Parents are often perceived by adolescents with LTCs as encouraging their participation in discussions and decision-making, which facilitates their involvement (155). Additionally, child-parent collaboration in long-term healthcare decision-making can facilitate positive incorporation of the selected healthcare option within the family life (156-158)

However, parent proxy reports do not always reflect the adolescents' views. For example, discordance has been reported between adolescents' and parents' perceptions of health-related quality of life, with the parent generally scoring their child's quality of life lower than the adolescent themselves (159, 160). This could reflect parents' perceptions of their child's LTC as having a much larger impact on their lives and may emphasize parents' wider experiences; they understand what their children may be missing. Parents often report that their children are restricted by their LTC, whereas adolescents with LTCs may not perceive the same restrictions or play down or not acknowledge the extent to which they are restricted by their condition (161). In addition, parents may prefer their adolescents to have lesser degree of participation in decision making than the adolescents desires (162, 163). Parent-adolescent dyads can differ in terms of the type of information they deem appropriate; adolescents generally want more information relating to the implications of their condition whereas parents may prefer to be more protective over the information their child receives (163). Therefore, although the parents' roles are crucial in supporting adolescents during consultations and through the decision-

making processes, it is also important for adolescents' voices incorporated into the discussions where possible and parents can play a pivotal role in helping this to happen.

1.6 Developing and evaluating theory and evidence-based complex interventions

Efforts to facilitate adolescent involvement in decision-making send the message that their voice is important and creates an expectation for increased participation as they grow older. Adolescents identify themselves as having different needs to children and adults, and prefer their care to be adapted as such (164, 165). Therefore, it is important to develop interventions based on their views, addressing their accounts and preferences. The SDM model is built on the premise that patients are experts in the decision-making process, they have important knowledge and understanding of their needs. Therefore, the input of adolescents with LTCs is crucial to the development of an intervention for them. Furthermore, the effectiveness of LTC healthcare interventions can be more relevant to the target population if patients' insights into the management of their condition are incorporated (166). Adolescents with LTCs have previously demonstrated their ability to contribute to the development of interventions aimed at encouraging involvement during consultations, thus increasing the potential for intervention acceptability among this population (164).

Complex, unlike simple, interventions typically have several interacting components and non-linear causal pathways to a new behaviours by the targeted population (167). Other characteristics of a complex intervention include the ability to be adapted and tailored; the complexity of the behaviours required by those delivering and receiving the intervention; and the variety of outcomes it may yield (167). Careful development of complex interventions, including an effective implementation plan, is necessary in order to increase the chance of intervention effectiveness when evaluated, and ultimately being adopted widely in the real world (168). Best practice is for interventions to be developed systematically, using the best available evidence and appropriate theory, then to be tested using a carefully phased approach (167, 169). In 2000, the Medical Research Council (MRC) first published a framework for design and evaluation of complex health interventions, in order to help researchers and research funders to recognise and adopt appropriate methods (170).

1.6.1 Medical Research Council guidance for intervention development.

The MRC framework (2008) is a guide for the development and evaluation of complex interventions to improve health, and will be followed to develop the intervention described in this PhD (167, 169). This framework has been highly influential in health interventions development, and the associated British Medical Journal paper is widely cited (170). The new MRC guidance emphasises a more flexible, less linear intervention development process than the original publication in 2000, and recommends greater attention to the early phase development and piloting work (167, 169). The framework advocates a systematic, phased approach to intervention development and evaluation to ensure researchers fully understand, define, and document the development process in order to successfully evaluate the intervention, and enable replication, evidence synthesis, and wider implementation (167, 169). The MRC framework has been used extensively to successfully develop interventions aimed at improving health behaviour in adolescents with LTCs, including a psychosocial package to improve health outcomes such as glycaemic control in adolescents with type 1 diabetes, and an educational package to help adolescents with chronic pain to develop strategies to manage their stress and pain (171-179).The four phases of intervention development and evaluation are outlined in the framework, though these may not necessarily follow a linear sequence in practice (Figure 2).

Feasibility and piloting
▷ Testing procedures
▷ Estimating recruitment and retention
▷ Determining sample size

Development
▷ Identifying the evidence base
▷ Identifying or developing theory
▷ Modelling process and outcomes

Evaluation
▷ Assessing effectiveness
▷ Understanding change process
▷ Assessing cost effectiveness

Implementation
▷ Dissemination
▷ Surveillance and monitoring
▷ Long term follow-up

Figure 2. The key elements of the MRC intervention development and evaluation process (167, 169)

During the first phase (development), researchers should identify the evidence base, relevant theory and model processes, and outcomes of the intervention. The development phase for this thesis will be described in Chapters 2 to 6, using primary and secondary data. The second phase, (feasibility and piloting) encourages initial testing of the acceptability and feasibility of the intervention prior to a full-scale evaluation (phase 3). Although phase 2 did not fit into the remit of this PhD, a protocol for a feasibility and pilot RCT with a process evaluation will be proposed and outlined in detail in Chapter 7. The third phase (evaluation) involves assessing the effectiveness and cost effectiveness of the intervention and developing an understanding of the change processes involved for adoption and implementation. Following evidence of an acceptable, feasible, effective, and cost-effective intervention, the final phase (implementation) is carried out, which involves surveillance and monitoring of the intervention through longer-term adoption and follow-up.

1.6.2 Co-production in health research and intervention development

Co-production involves a working partnership by sharing power with social care and health service users (and their families) in service delivery, including intervention development, acknowledging that service users have knowledge and experience that can help improve services for themselves and others (180). As an example, the centre for Development, Evaluation, Complexity, and Implementation in Public Health Improvement at Cardiff University works with a group of young people (aged 14 to 25) to co-produce interventions aimed at improving young people's public health, such as reducing unplanned teenage pregnancy, where the young people act as research advisors, providing their views on health topics and research processes and materials.

 In 1996, INVOLVE, an organization that supports involvement in research, was set up in the UK by the National Institute for Health Research (NIHR) to guide and support patient and public involvement in NHS, public health, and social care research. INVOLVE defines patient and public involvement in research as: "*research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them"* (181). Ways in which patients and the public can be involved in research projects include as grant holders or co-applicants; in identifying research priorities; as members of a steering group; commenting on research materials such as

information sheets; undertaking interviews with participants; and assisting in research analysis and dissemination (181). Involving those who are affected by the research and successive intervention development can improve research and intervention quality and relevance by providing an alternative perspective from the service user viewpoint, thus improving research and intervention appropriacy and acceptability for the target population (181-184).

The involvement of adolescents with LTCs in co-producing research and intervention development has received increasing attention in policy and practice (185, 186). Stated outcomes include increased inclusivity and accessibility of initiatives and research environments, with adolescent co-researchers describing the experiences as empowering and rewarding (182, 187, 188). However, reviews of studies involving children and adolescents with LTCs as partners in research found an absence of detail of co-production practices or methods to assess co-production processes and outcomes (189, 190). Co-production with adolescents with LTCs is characterised by heavy demands of time, work, and resources (182, 187, 191, 192) and despite the benefits to all those involved in the research process, complete intervention co-production does not fit into the scope of this PhD thesis. However, I will attempt to include elements of co-production, involving adolescents at the various stages of intervention development.

1.7 Addressing the gap

Adolescents with LTCs have been underrepresented in the past, both in clinical encounters and in research (114, 143). To date, research has mainly focused on understanding and overcoming HCPs' perceived barriers to SDM in paediatric medicine (145, 152, 193, 194). Furthermore, much research undertaken to understand experiences of adolescents with LTCs has focused on the perceptions of HCPs and parents (195-199). A systematic review and meta-analysis of paediatric SDM interventions retrieved 61 studies, of which only 13 (21%) included patients in the target audience, and just four (7%) aimed at patients alone (114). All but two of the patient targeted interventions could not be included in the meta-analysis due to lack of formal evaluation.

Although it was found that SDM interventions may improve knowledge and decisional conflict in parents, the outcomes for young patients are left unknown

(114). In addition, the majority of the interventions were decision aids with a limited number of interventions designed to promote SDM (114). As mentioned before, decision aids can facilitate SDM, but can only be useful when a patient understands and wants to participate in SDM. The above demonstrates a gap in the academic and clinical knowledge base regarding adolescents' experiences around involvement in decision-making, and how to prepare and support the participation of adolescents with LTCs in SDM.

This thesis will therefore attempt to bridge this gap by exploring the perspectives of adolescents with LTCs around decision-making involvement and developing a patient-targeted complex intervention to prepare and support their involvement in SDM with HCPs, based primarily on patient-reported barriers and facilitators to engaging with the SDM process.

1.8 Thesis aims and objectives

The primary aim of this PhD is to develop a theory- and evidence-driven intervention targeted at adolescents with LTCs to prepare and support their involvement in SDM about their healthcare. This will be guided by the MRC framework for complex intervention development alongside relevant theory to ensure that the mechanisms underlying the behaviour (participating in SDM) can be understood in terms of a theoretical framework and are addressed in the content of the intervention. This is important because theory can be used to guide intervention content and facilitate the selection of suitable evaluation measures. As discussed above, and in the chapters to follow, there has been limited work to date exploring the perspectives of the adolescents themselves around participating in SDM. Therefore, in order to inform the intervention development, the secondary aim of the PhD is to understand perceptions of adolescents with LTCs around barriers to, and facilitators for SDM. This will be explored using primary qualitative data (participatory interviews) and secondary systematic review data.

There are six objectives of this PhD, which are to:

(1) understand the preferences and experiences of adolescents with LTCs around involvement in decision-making about their healthcare
(2) identify relevant theory and approaches for intervention development

(3) explore the perceptions of adolescents with LTCs around barriers to, and facilitators for SDM

(4) develop a theory- and evidence-based intervention to prepare and support the participation of adolescents with LTCs in SDM

(5) pre-test the intervention with potential users (adolescents with LTCs and HCPs)

(6) propose an implementation plan and a protocol for testing the intervention in order to inform formal evaluation (RCT).

1.9 Thesis overview

Chapter 2

This chapter describes a systematic review and narrative synthesis of the literature up to March 2017, with a section describing additional literature identified between this date and September 2019. It reports data generated from adolescents with LTCs regarding their perspectives around being involved in decision-making about their healthcare, including decision-making experiences and preferences.

Chapter 3

Chapter three presents the theoretical underpinning of this thesis. Heath behaviour theories relevant to the involvement of adolescents with LTCs in SDM will be described and critically evaluated. Approaches to intervention development in line with the theoretical models will also be discussed.

Chapter 4

The findings from a participatory qualitative interview study with nineteen males and females aged 12 to 19 with long-term physical health conditions recruited from paediatric and young adult (transitional) rheumatology, endocrinology, neurology, and nephrology clinics are reported in Chapter 4. Individual factors, such as self-efficacy around decision-making, and the wider socio-environmental factors (i.e., social norms) are explored and discussed in terms of their influences on the involvement, or lack thereof, of adolescents with LTCs in SDM. This Chapter also reports participants' intervention suggestions including design, content, and delivery.

Chapter 5

Chapter 5 describes the systematic process that was used to develop a prototype for an intervention for adolescents with LTCs to prepare and support their involvement in SDM based on findings from Chapters 2 to 4. The Person-Based approach (200)

combined with the Intervention Mapping Approach (201) and Theoretical Domains Framework (202) were used to guide the development process.

Chapter 6

This Chapter presents the findings from pre-testing the intervention prototype with four focus groups consisting of a total of fourteen adolescents, aged 13 to 19, with endocrinological and renal conditions, as well as six interviews and one focus group with a total of fourteen clinical team members who care for adolescents with LTCs. The think-aloud method (203) was used to test the specific intervention components, including key phrases and visuals proposed to portray the main ideas, in order to gauge intervention acceptability, usefulness and comprehension before final production. Adolescents with LTCs and HCPs provided suggestions for improvement and implementation, which are reported in this chapter.

Chapter 7

Chapter 7 proposes a protocol for intervention testing prior to a full-scale evaluation. The implementation process is described and outlined. The method for undertaking a feasibility and pilot RCT with embedded process evaluation is detailed, and suggestions are presented.

Chapter 8

The concluding chapter summarises the key findings of the thesis in relation to relevant literature and highlights its novel contributions to existing knowledge. Methodological limitations and implications of findings are discussed. Suggestions for further evaluation and potential for implementation are provided.

Chapter 2: What adolescents living with long-term conditions say about being involved in decision-making about their healthcare: A systematic review and narrative synthesis of preferences and experiences

2.1 Chapter overview

This chapter presents a systematic review of the literature reporting adolescents' perceptions around being involved in decision-making about their healthcare, including their experiences and preferences around involvement. A version of this chapter was published in the academic journal *Patient Education and Counseling* in October 2018 (204) (appendix 1). This review offers significant contribution to Objective 1 of this thesis and is the first step to informing the intervention development, granting a thorough reflection on the empirical work emerging in the area of healthcare decision-making with adolescents with long-term conditions (LTCs).

2.2 Introduction

2.2.1 Background

The Person Based Approach to behaviour change intervention development (discussed in detail in further detail in Chapter 3) involves firstly developing an understanding of the perspectives and lives of the target audience (200). This approach outlines that in the first stage of intervention development (intervention planning) it is recommended to first "*synthesise previous qualitative studies of user experiences of similar interventions*" (200). Prior to conducting the systematic review reported in this chapter, a scoping search was carried out to enable mapping of the available evidence in order to specify the review question and refine the search strategy and selection criteria. A number of papers were identified which describe the development of interventions targeted at adolescents with long-term conditions (LTCs) to promote shared decision-making (SDM) (164, 205-207). However, at this time (January 2017), only two pre-existing evaluations of such interventions were found; one being a decision aid (208) and the other aimed to promote adolescents' participation in asthma consultations (209). Evidence reveals that SDM in paediatric consultations is not a normal occurrence (143, 148, 210-212). As such, this chapter presents a systematic review of literature and narrative synthesis which aims to

answer the question: what are preferences and experiences of adolescents with long-term conditions (LTCs) around decision-making about their healthcare?

As outlined in chapter 1, adolescents with LTCs increasingly take responsibility from their patents for condition management tasks as they grow older (28-32). However, the same level of responsibility is not reflected in the decision-making about their healthcare (143, 211). It is important to understand how adolescents experience discussions and decision-making during consultations in a healthcare setting, as well as their preferences for involvement. Understanding the perspectives of adolescents with LTCs regarding their experienced and desired roles in the decision-making process can help us to further understand their support needs.

2.2.2 Chapter aim and objectives

The aim of this review was to collect and synthesise published research data on adolescent perspectives towards involvement in healthcare decision-making. The objectives were to: (a) understand the preferences of adolescents with LTCs towards being involved in the decision-making process about their condition management; (b) understand the experiences of adolescents with LTCs with involvement in the decision-making process and (c) use these findings to inform, in part, the development of an intervention aimed at supporting SDM with this population (see Chapter 5).

2.3 Methods

2.3.1 Systematic review

Systematic reviews are increasingly important summaries of the existing evidence in relation to a particular phenomenon, and are a key element of evidence-based healthcare (213). This review applied a systematic search methodology following Khan et al's (213) five steps, the PRISMA statement reporting guidelines to format the report, (214) and in accordance with the guidance on the conduct of a narrative synthesis (215). The five steps include framing the research question, identifying relevant publications, assessing study quality, summarising the evidence, and interpreting the findings (Table 2). The question to be addressed by the review should be specific, clear, and unambiguous, and framed before beginning the review work. This often involves identifying a specific population, type of exposure, outcome, and study design. For example, the PICO (population, intervention, control

or comparison, outcomes) model is often used to formulate the research questions in systematic reviews and meta analyses of clinical trials testing a specific intervention or intervention type (216). The SPICE (setting, perspective, intervention, comparison, evaluation) framework builds on PICO, recognising the subjectivity of social science research and encouraging a broader evaluation framework by splitting the 'population' component into 'setting' and 'perspective' and replacing "outcomes" with "evaluation" (217). Like PICO, this model is more suitable for studies where there are two or more groups to compare, and less so for the inclusion of exploratory, qualitative studies.

Due to the limited research area and therefore the inclusion of all types of research design in this review, the SPIDER tool (218) was used to refine the research question and search strategy. The SPIDER tool, which can be applied to qualitative, quantitative, and mixed methods research, involves identifying the sample, phenomenon of interest, design, evaluation, and research type of the studies that are to be included (Figure 3). A preliminary search was conducted to identify potentially eligible studies in order to refine the research question and eligibility criteria.

S — **Sample:** Adolescents (aged 10 to 19) living with a long-term condition (conditions requiring 'ongoing management over a period of years or decades)

PI — **Phenomenon of Interest:** Adolescent involvement in decision-making in a healthcare setting

D — **Design**: Any theoretical framework or absence thereof

E — **Evaluation:** Adolescents' preferences and experiences

R — **Research type:** Qualitative, quantitative and mixed methods

Figure 3. Adapted SPIDER tool for qualitative evidence synthesis (218)

The PRIMSA statement (214) includes a 27-item checklist of preferred reporting items (such as: explicit objectives and rationale, protocol registration, and describing any funding sources) as well as a flow diagram outlining the four phases of the systematic search process: identification, screening, eligibility and inclusion (Figure

4). PRISMA was used to guide the reporting process outlined in the systematic review protocol, which was prospectively registered on PROSPERO (219) (CRD42017055650).

Table 2. Five stages of a systematic review adapted from Khan et al. (213)

1. Framing the Question
- The problem to be addressed by the review must be specified in the form of a clear and unambiguous question before beginning the review work: what are the preferences and experiences of adolescents with LTCs around involvement in decision-making about their healthcare?

2. Identifying Relevant Work
- The search should be extensive and include multiple databases. For this review I used Embase, Medline, Cochrane Library, CINAHL, PsycINFO and Scopus, as well as a grey literature search. The inclusion/exclusion criteria should be justified and flow directly from the research question. This has been outlined in table 3.

3. Assessing Quality
- Quality assessment is relevant to every step of the review. This helps in assessing the strength of inferences and making recommendations for future research. This was done using existing criteria designed for appraising the appropriate type of study (CASP/AXIS/MMAT) .

4. Summarising Evidence
- The data from the studies were extracted according to basic study characteristics, including study aims, design, sample demographics, and care setting; definition of decision-making involvement and adolescent reported preferences and experiences. Given the homeogeneity of existing studies, I opted for a narrative sysnthesis as a means of data analysis.

5. Interpreting findings
- This review is limited according to the available literature and inclusion/exclusion criteria, and limits the scope of findings accordingly. I discussed the findings in terms of how to improve care for adolescents with LTCs by promoting the notion of shared-decision-making, and informing intervention development.

2.3.2 Eligibility criteria

Included studies were English-language qualitative, quantitative, and mixed-method papers which report empirical research about the preferences and/or experiences of adolescents living with one or more LTCs, from the patient perspective. Non-English language sources were excluded due to a lack of translation resource. No limitations were placed on the year of publication. An age range of 10 to 19 years was stipulated in accordance with the World Health Organisation (WHO) definition of adolescents. Studies with participants of an age outside the pre-defined adolescent parameters were included if the study's measure of central tendency (e.g., mean, mode or median) fell within the 10 to 19-year-old range. LTCs were defined as conditions requiring '*ongoing management over a period of years or decades*' (5);

meaning conditions which require continuing clinical care and self-management. Examples include diabetes, asthma, and cancer. Due to the small number of eligible papers, studies were not excluded if the sample also included participants with acute conditions.

For inclusion, papers had to examine the decision-making process in a healthcare setting regarding decisions that are characteristic to LTC care. This means ongoing condition management discussions and decision-making, such as decisions about, diet, exercises, appointment scheduling, medication administration, or treatment plans. Papers which primarily examined other types of decisions such as research participation, fertility preservation, or end of life decisions, were excluded. Studies containing mixed samples (e.g., perspectives of adolescents, parents, and HCPs) were included if the adolescents generated data were reported separately or could be separated by the reviewers. Data which made comparisons between adolescent and HCP/parent responses were retained. Papers which reported studies with wholly parent or HCP samples were excluded. The inclusion/exclusion criteria for this systematic review are outlined in Table 3.

2.3.3 Systematic search

A Cardiff University School of Medicine subject librarian (MH) assisted with the development of the search strategy, including identification of search terms and appropriate databases. Six electronic bibliographic databases (Embase, Medline, Cochrane Library, CINAHL, PsycINFO and Scopus) were searched systematically from inception to March 2017 to identify potentially eligible articles. Ethos, Open Grey, The New York Academy of Medicine Library and ADOLEC (Adolescent Health) were searched for grey literature, such as documents published by governments and non-governmental organisations. A comprehensive strategy was developed with key search terms across titles and abstracts, or as medical subject headings using the Boolean operators 'AND' to combine key concepts, and 'OR' for synonymous keywords (Table 4). Key search terms included a string relating to 'adolescents', and combinations of strings for decision-making and HCPs, which was adapted from the Legaré et al. Cochrane review (220). Due to the inability to stipulate all possible LTCs, and difficulty defining 'preferences' and 'experiences', no strings for these were included in the strategy, and the exclusion process was done during eligibility screening. The search was piloted to ensure that it retrieved

previously identified qualifying papers. Relevant papers were also sought using the 'pearl-growing' technique, in which further studies are identified by examining the reference pages of relevant papers (221).

The PRISMA statement (214) was used as a guide to report the study selection process. The papers identified from the initial database searches were imported to EndNote X8 (222) and duplicates removed using the deduplication function. Remaining titles and abstracts were then screened for relevance; those that did not meet the inclusion criteria were removed. The full texts of all the remaining records were assessed independently for eligibility by a second reviewer and colleague who was a NIHR Doctoral Fellow in the division of Population Medicine at Cardiff University at the time, with training and experience in conducting systematic reviews (VS). Papers were assessed according to the inclusion/exclusion criteria (Table 3) and the reasons for exclusions stated (Figure 4). Resolution of discrepancies was sought through discussion involving a third researcher and supervisor of this PhD thesis (FW).

Table 3. Systematic review inclusion/exclusion criteria

Inclusion	Exclusion
• Adolescent (aged 10-19 sample). Studies with participants from slightly outside these parameters will be included, as long as the focus and age measure of central tendency falls within the 10-19 age bracket. AND • Participants with any one or more specified chronic conditions, which according to the WHO definition is describes as persisting for a minimum of three months. AND • Studies examining patient participation decision-making around condition management. AND • Studies providing account of SDM between patient and HCP. AND • Studies which include experiences and/or preferences from the perspective of the adolescent participants.	• Age measure of central tendency outside of the 10-19 bracket or focus on young adults or young children. OR • Participants with only acute or unspecified conditions. OR • Studies which identify other types of decision-making. For example, concerning end of life care, fertility preservation, risk behaviours, research participation or any other decision not characteristic of condition and/or symptom management. OR • Studies providing account of SDM between parent and healthcare professional or parent-adolescent only. OR • Studies which include perspectives of only the parents and/or HCPs, and/or observational data only.

Table 4. Example Search Strategy: OVID - Medline

#1
shared decision*.ti,ab. or sharing decision*.ti,ab. or informed decision*.ti,ab. or informed choice*.ti,ab. or decision aid*.ti,ab. or ((share*.ti. or sharing.ti. or informed*.ti.) and (decision*.ti. or deciding.ti. or choice*.ti.))

#2
*clinical decision making/ or *decision making/or *decision support system/ or *ethical decision making/ or *family decision making/ or *medical decision making/ or *patient decision making/or decision making*.ti,ab. or decision support* ti,ab. or choice behaviour*.ti,ab. or ((decision*.ti. or choice*.ti.) and (making*.ti. or support*.ti. or behaviour*.ti.))

#3
patient participation/ or patient participation.ti,ab. or consumer participation*.ti,ab. or patient involvement*.ti,ab. or consumer involvement*.ti,ab. or ((patient*.ti. or consumer*.ti.) and (involvement*.ti. or involving*.ti. or participation*.ti. or participating*.ti.))

#4
*doctor patient relation/ or *nurse patient relationship/or ((*nurse/ or *physician/ or nurse*.ti or physician*.ti or clinician*.ti. or doctor*.ti. or general practitioners*.ti. or gps*.ti. or health care professionals*.ti. or healthcare professionals*.ti. or health care providers*.ti. or healthcare providers*.ti. or resident*.ti.) and (*patient/ or patient*.ti. or consumer*.ti. or people*.ti.))

#5
*child/ or *adolescent/ or kid*.ti,ab or *minors/ or minor*.ti, ab or child*.ti,ab. or pediatric*. ti,ab. or paediatric*.ti,ab. or adolescen*.ti,ab. or youth*.ti,ab. or teen*.ti,ab. or (young adj3 people).ti,ab. or (young adj3 person).ti,ab.

#6
(1 or (2 and 3) or (2 and 4) or (3 and 4)) and 5

2.3.4 Data extraction

The data from the qualifying studies were extracted according to basic study characteristics, including study aims, design, sample demographics, and care setting (Table 5), as well as definition of decision-making involvement and adolescent reports of preferences and experiences around decision-making involvement. Where necessary, corresponding authors of included studies were contacted to obtain specific information. The second researcher (VS) extracted the data for all the included studies independently. The relevant data were entered into NVivo11 for coding support and quotation retrieval (223).

2.3.5 Data synthesis

Due to the lack of homogeneity in the eligible studies, a meta-analysis of the results was impossible. Lucas et al. (224) describe examples of alternative methods for synthesising heterogeneous designs, and explain that textual narrative synthesis is well suited for reviewing the existing body of literature, along with identifying gaps which need to be filled. A narrative synthesis was therefore conducted following Popay et al's (215) guidance. This involves using words and text to summarise and explore data from differing methodologies and organising the output as a synthesis to 'tell a story'. A preliminary synthesis was developed involving the coding and organising the extracted data which were relevant to the research question. The first step was the extraction of relevant data, which were entered into NVivo11 (223). Braun and Clarke's (225) six-step thematic analysis was used to extract, code, organise and report patterns or themes of the relevant data. The dataset was coded inductively, and the codes were grouped into overarching themes. The themes were discussed with the PhD supervisors, and refined until a coherent pattern had been formed, and a summary of each theme was written. The included studies were then revisited to ensure the themes provided a sound representation of the relevant, extracted data.

2.4 Results

2.4.1 Search results

The searches retrieved 10,388 studies; 6572 were assessed against the inclusion criteria after duplicates were removed, and 27 papers (102, 162, 163, 208, 226-247) were included in the review (Figure 4). Studies originated from seven countries:

nearly half (n=11) from the United States, other countries of origin include Canada (n=2), Australia (n=2) and European countries (n=12). All except three were published between 2006 and 2016. Included studies employed qualitative (n=17), quantitative (n=6), and mixed methods (n=4). Study samples included adolescents with cancer (163, 229, 232, 236, 241-243, 245, 247, 248), diabetes (231), cerebral palsy (234, 246), immune thrombocytopenia (227), a mix of LTCs (102, 208, 226, 235, 238-240) or LTCs and acute illnesses (229, 237, 244). No studies focussing on adolescents with mental health conditions met the inclusion criteria. Study characteristics are reported in Table 5.

Records identified through database searches (n=10338)
- OVID-Embase (n=3056)
- OVID-MEDLINE (n=2256)
- OVID-PsycINFO (n=1083)
- CINAHL (n=1415)
- Cochrane Library (n=383)
- Scopus (n=2145)

Additional records identified through other sources: (n=10)
- Grey literature search (n=2)
- Screening references of relevant papers (n=8)

Records after duplicates removed (n =6562)

Records screened (n =6572)

Records excluded after scanning titles and abstracts (n =6491)

Full-text articles assessed for eligibility (n = 81)

Full-text articles excluded (n =54)

- Only abstract available (n=4)
- Patient participants are not mostly adolescents (n=13)
- Participants do not have LTCs (n=7)
- No patient generated data regarding attitudes and/or experiences towards decision-making involvement (n=21)
- Decision-making does not concern ongoing illness management (n=5)
- Decision-making does not take place in a healthcare setting (n=4)

Studies included in qualitative synthesis (n =27)

Figure 4. PRISMA (214) flow diagram with reasons for exclusion

Table 5.Table of included studies

Study: Author, year, Country	Study aims	Design	Patient population characteristics	Health Condition(s) and setting	Patient Age range	Definition of involvement
Angst and Deatrick, 1996 (226) United States	To describe how children with LTCs and their parents are involved in health care decisions through a secondary analysis of two data sets	Qualitative: interviews	N=28 46% female	Cystic fibrosis (71%) and scoliosis (29%)/ Secondary care	7 to 19	Contribution towards decisions related to their health or illness
Beck *et al*, 2014 (227) Canada	To examine the treatment decision-making process for hospitalised children	Qualitative: focus groups	N=7 14% female	Immune thrombocytopenia/ Secondary care	10 to 18	SDM: exchanging information about medical evidence and patient's preferences, and identifying which course of action is most consistent with those preferences
Bejarano *et al*, 2015 (208) United States	To evaluate the feasibility and acceptability of SDM interventions	Quantitative : Pre-post experimental design	N=26 50% female	Environmental allergies (58%) and scoliosis (42%)/ Secondary care: specialist clinic	5 to 17	SDM: accommodating patient preferences and values in making decisions about their care
Coyne, 2006 (228) United Kingdom	To explore children's, parents', and nurses' views on participation in care in the healthcare setting	Qualitative: in-depth interviews and participant observation	N=11 64% female*	Various long-term and acute/ Secondary care: inpatient	*7 to 14	Being consulted and involved in decisions about their care
Coyne & Gallagher, 2011 (229) Ireland	To explore hospitalised young people's experiences of participation in communication and decision-making	Qualitative: interviews and focus groups	N= 55 44% female	Various long-term and acute/ Secondary care: Inpatient	7 to 18	Being active partners in decisions about their health and care and, where possible, being able to exercise choice
Coyne *et al*, 2014 (230) Ireland	To explore children's participation in shared decision-making.	Qualitative: interviews	N= 20 45% female	Cancer/ Secondary care: Inpatient and day care units	7 to 16	SDM: contribution to the decision-making process, independent of who makes the final decision.
Croom, 2011 (231) United States	To examine the relationship between perceived patient-centred communication and patient empowerment and diabetes management.	Quantitative: Cross-sectional surveys and medical records	N=190 52% female	Type 1 diabetes/ Secondary care: specialist clinic	10 to 15	Mutual exchange of information and reaching a shared understanding of patient problems and the treatments that are concordant with patient values.
Dumsmore & Quine, 1995 (232) Australia	To identify patient's information, support and decision-making needs and preferences, and the extent to which those needs were being met.	Mixed Methods: Questionnaire including open/ closed-ended questions	N=51 47% female	Cancer/ Secondary care	12 to 24	Information provision, and decision-making involvement.

Ellis & Leventhal, 1993 (163) United States	To evaluate the information needs and decision-making preferences of children with cancer.	Quantitative: surveys	N=50 40% female	Cancer/ Secondary care	9 to 17	Information needs and decision-making preferences
Feenstra *et al*, 2015 (233) Canada	to evaluate the feasibility and acceptability of decision coaching	Quantitative: Pre-test/post-test	N=7 43% female	Type 1 diabetes/ Secondary care: specialist clinic	9 to 17	SDM: exchange of information on options and treatment preferences to reach an agreement on treatment plan.
Garth *et al*, 2009 (234) Australia	To explore how the doctor–parent–child partnership is experienced and if the child patient is considered a contributor	Qualitative: Interviews	N= 10 70% female	Cerebral palsy/ Secondary care	8 to 12	Factors contributing to an effective partnership which include joint decision-making and open communication
Jedeloo et al., 2010 (235) The Netherlands	To uncover preferences for self-management and hospital care of adolescents with various long-term conditions.	Mixed methods: Interviews Q-methodology	N=31 48% female	Various long-term / Secondary care	12 to 19	Involvement in consultations including decision-making styles.
Kelly *et al*, 2016 (236) United States	To better understand how children and adolescents viewed their treatment decision-making involvement	Qualitative: interactive interviews	N=29 48% female	Cancer/ Secondary care	9 to17	Information provision and involvement in treatment decision- making
Kelsey *et al*, 2007 (237) United Kingdom	To explore young people's perceptions of their involvement in healthcare decisions affecting their management of care.	Qualitative: Interviews and recorded audio diaries	N=10 40% female	Various long-term and acute/ Secondary care: Inpatient	13 to 16	Involvement in healthcare decisions
Knapp *et al*, 2008 (238) United States	To explore adolescents' involvement in and preferences about SDM	Mixed methods: Surveys and interviews	N=35 55% female	Various long-term/ Various care settings	14 to 21	SDM: participation in the decision-making by expressing preferences and coming to a mutual decision.
Knopf *et al*, 2008 (162) United States	To describe the decision-making preferences of adolescents with long-term conditions and their parents	Quantitative: surveys	N=82 55% female	Various long-term conditions /Secondary care	*11 to 19	SDM: shared information and collaboration to reach a decision
Lipstein *et al*, 2013 (249) United States	To understand adolescents' roles and preferences in long-term condition treatment decisions, using biologic therapy decisions as an example.	Qualitative interviews	N=15 60% female	Chron's disease (47%) and Juvenile idiopathic arthritis (53%)/ Secondary care	12 to 17	Participation in medical decision-making
Lipstein *et al*, 2016 (240) United States	To compare factors considered by parents to those considered by adolescents making decisions about long-term condition treatments.	Qualitative interviews	N=13 62% female	Chron's disease (54%) and Juvenile idiopathic arthritis (46%)/ Secondary care	13 to 18	Participation in LTC treatment decisions
Ruhe *et al*, 2016 (a) (241) Switzerland	To explore patients' perspectives in on participation in discussions and decision-making surrounding their diagnosis.	Qualitative interviews	N=17 35% female	Cancer/ Secondary care	9 to 17	Participation in the form of receiving or providing information, contributing an opinion, or making healthcare choices

Ruhe *et al,* 2016 (b) (242) Switzerland	To explore how patient participation was put into practice in a paediatric oncology setting	Qualitative interviews	N=17 35% female	Cancer/ Secondary care	9 to 17	Participation in discussions and decision-making
Stegenga & Ward-Smith, 2008 (243) United States	To explore treatment decision-making from the perspective of the adolescent	Qualitative interviews	N=3 67% female	Cancer/ Secondary care	13 to 15	Participation in treatment decision-making
Taylor *et al.*, 2010 (244) United Kingdom	To investigate child and carers' attitudes towards child involvement in paediatric consultations	Qualitative interviews	N=20 75% female	Various acute and long-term / Secondary care: inpatient and outpatient	7 to 16	Involvement during consultations including information sharing and ultimate decisions about treatment
Van Staa, 2011(102) The Netherlands	To evaluate adolescents' preferences and competencies for communication during consultations.	Mixed methods: Interviews, Q-methodology, Observations, Focus groups, Web questionnaire	N=1021 55% female	Various long-term/ Secondary care	12 to 19	Healthcare communication, including making decisions
Weaver *et al,* 2015 (245) United States	To investigate adolescent medical decision-making preferences and behaviours reported to be supportive of their preferred level of decision-making involvement.	Qualitative Interviews	N=40 40% female	Cancer/ Secondary care	12 to 18	Treatment decision involvement and information access.
Young *et al,* 2006 (246) United Kingdom	To examine and compare children's, parents' and practitioners' perspectives and experiences of decision-making in community paediatric physiotherapy services	Qualitative Interviews and focus groups	N=11 45% female	Cerebral palsy/ Community care	8 to 18	SDM: involvement in the decision-making process by sharing information and expressing treatment preferences so that a decision is made and agreed by all parties
Zwaanswijk *et al,* 2007(247) The Netherlands	To investigate communication preferences of childhood cancer patients, parents, and survivors of childhood cancer	Qualitative Online focus groups	N=7 57% female	Cancer/ Secondary care	8 to 16	Communication, including information exchange, decision-making and interacting.
Zwaanswijk *et al,* 2011 (248) The Netherlands	To investigate communication preferences and variables associated with these preferences.	Quantitative hypothetical : Vignettes and questionnaires	N=34 38% female	Cancer/ Secondary care	8 to 16	Level of involvement in decision-making

*Author contacted directly for participant information which was not available in published report

2.4.2 Critical appraisal of included studies

Quality of the included studies was assessed using existing criteria designed for appraising the appropriate type of study; qualitative Critical Appraisal Skills Programme (CASP) (250), Appraisal tool for Cross Sectional Studies (AXIS) (251) and Mixed Methods Appraisal Tool (MMAT) (252). These tools do not attach scores to the assessed criteria, instead are used to indicate whether the criteria have been met, unmet, or whether it is unclear. Quality was assessed according to each domain on the appropriate checklist which include rationale of study, methodology, design, recruitment strategy, data collection and analysis, ethical issues, reporting of findings, and contribution to research. Ten per cent of the included studies was quality assessed by the second researcher independently (VS). Both researchers were in agreement regarding study quality achievements and issues, therefore it was decided no further duplication of effort was required. Due to the small number of eligible studies, none were excluded on the basis of overall quality, but important methodological issues were noted and taken into consideration during the data synthesis.

All papers were appraised as including a clear statement of aims with an appropriate research methodology, and design to address the aims. Of the qualitative and mixed methods studies, issues of reflexivity were only considered in one paper (245). This is especially important due to the potential for perceived power imbalance between the researcher(s) and young participants, and it is important to consider the researchers' own role(s), potential bias, and influence on the research outcomes. Furthermore, non-respondent characteristics were not reported in most studies. These data could be meaningful due to a potential association between those who participate in research and those who are involved during health consultations. Three papers did not include a clear recruitment strategy, and one paper did not state any limitations to the study (102, 226, 232). Six papers had insufficient detail concerning ethical considerations, two of which did not note whether or to which board ethical approval had been sought or achieved (102, 226, 241, 243-245). These details are important considering the risk of vulnerability of the participants.

Of the quantitative studies, all papers were credited for having a sampling strategy relevant to the research question, clearly outlining the calculation of statistical significance, and including sufficient information for the study to be repeated.

However, none of the studies reported whether the sample was representative of the target population or if the measures used were to address and categorise non-responders.

Of the mixed methods studies, all papers were appraised for having relevant data sources appropriate for the research question and containing a relevant research design to undertake a quantitative and qualitative research question. However, none of the studies discussed issues around reflexivity nor any limitations associated with the integration of qualitative and quantitative methods.

All but two papers provided clear and explicit findings, which add a valuable contribution to the area of literature (102, 162, 163, 208, 226-237, 239-242, 244-247).

2.4.3 Synthesis of findings

The data reflected experiences of involvement in the decision-making process from the adolescent perspective, where parents, adolescents and HCPs were involved at varying levels. This includes involvement in the exchange of information, as well as discussions around options and decisions. In response to the first two review objectives the extracted data were grouped as either preferences or experiences. Preferences refers to the expressed wishes, views, and opinions of the young patients towards the different decision-making stages. Experiences represents the young person's reality, what they have experienced and how it affects them. The grouping of data into preferences and experiences allowed for comparisons to be made between what adolescents want, and what their reality is. Codes were created and grouped into three overarching themes and are summarised below (number of studies coded at each theme). Table 6 provides examples of quotations coded at each of the themes.

Table 6. Overarching themes and exemplar quotations

Theme and definition	Illustrative Quotations
Variability in involvement preferences and experiences: Involvement preferences and experiences can vary within and between individuals and can depend on factors such as type of decision and current health status.	*'Like, small, if they were to ask you do you want tablets or medicine, yea, of course you can make them decisions, it's your body, you should decide what you want to do like.'* (Female, aged 13) (229). *'In the beginning I did not care … because I was so shocked. But then, after a while I realized that I have to know what I have and what is going on. And then I started to listen again.'* (Male, aged 13-15) (241). *'I think that depends on the situation. Like for how much the decision will impact or affect me and how much it will impact or affect them [parents].'* (Male, aged 17 with cancer) (245).
Power dynamics and involvement in the decision-making process: Adolescents feel that it is their right to be involved and would like to be able to choose their level of involvement. However, they perceive parents and health professionals as having this control and look to them to support and encourage their involvement.	*'I think decisions are made most of the times before they come to me like the medicine and everything like, all the… they have already decided what to do before they come to me and ask me.'* (Male, aged 18) (229). *'They don't explain everything. The first time I was getting it; I didn't know what it was. He didn't say it when I was there. He said it to Mam behind the curtains. I was upset because I don't know what it's for or anything like that…I wouldn't have the guts to say anything, he comes across as a very intimidating man.'* (Female, aged 17) (229). *'They just tell you; they'd use big words and I wouldn't be able to understand them and then I'd ask my father what did they mean and he wouldn't really tell me. …. if the doctor is talking for nearly 15 minutes or so and your father only tells you a couple of seconds then there has to be more in the story. It makes you kind a worried.'* (Male, aged 11 with cancer) (229). *'He could have told me what he possibly thought it was. What he thinks they'll need to do. He could have told me anything more because it was almost like I was sat dead on the bed. He was talking to my mum, and that, but he could have been talking to me.'* (Male aged 13-16) (238).
Mismatch between involvement preferences and experiences: Adolescents report a disparity between their preferences and experiences, which can cause anxiety, and feelings of being unvalued and excluded.	*'If they at least told me, I think I would feel a little better about why I'm taking this medicine…I think I'd feel more comfortable if I got to talk to them.'* (Female with cystic fibrosis) (226). *'It made me feel a bit…a slight bit…like a piece of machinery actually, they weren't actually talking to me…I thought hey I'm the patient here, talk to me, explain what are you going to do'* (Female aged 14) (228). *'I feel real disappointed like, just disappointed because I don't feel, like I feel like I'm kind of rejected in a way.'* (Male, aged, 13) (229). *'I wish maybe they would have listened to my opinion a little more'* (Female, age 16 with junior idiopathic arthritis) (249). *'I prefer to represent myself. If I forget something, it's OK for my mum to step in, but I used to get so irritated when doctors addressed my parents instead of me, with me just sitting there*!' (Female, aged 19 with cystic fibrosis) (102).

2.4.4 Overarching themes

2.4.4.1 Variability in involvement preferences and experiences (n=24): From 'It's my body' to 'Doctor knows best'

Adolescents' involvement preferences and experiences vary substantially, which can depend on the individual, timing or the nature of the information being relayed, or decision type. Adolescents differ in the amount of information they would prefer to receive regarding sensitive topics, such as survival rates and prognosis in cancer treatment (247). Many report not wanting too much information when they are feeling acutely ill or too soon after diagnosis (102, 230, 234, 237, 241). Adolescents generally do not want to be involved in decision-making when feeling unwell, and become dependent on their parents to communicate with HCPs for them (230, 236). Relationships with, and support of, parents and HCPs, including trust, are often reported to affect experiences of involvement in decision-making (102, 228, 236, 237). Furthermore, adolescents report that with increased familiarity with HCPs they were able to become more assertive about treatment preferences (229).

 The preferred level of information and decision involvement is reported to evolve over time (226, 245), adolescents report wanting more information when they feel ready (241) and decision-making involvement increases as more information is obtained (236). Adolescents also state they would prefer more involvement as they get older (239). Age may influence involvement preferences, although this difference was normally only noted with younger adolescents (226, 236, 237). Adolescents under 11 years generally do not want the responsibility of being involved in decisions, and are satisfied with others making decisions for them, whereas those over 11 years report feeling frustrated when they are not involved (229). However, some studies found that age had no effect on involvement preferences or experiences (162, 226, 231, 245).

2.4.4.1.1 Types of decisions

Decisions are often categorised by adolescents as small or serious. Studies report that nearly all adolescents want and have input into smaller decisions such as medication administration or appointment scheduling (208, 226, 227, 229, 230, 236, 238, 241, 242, 245-247). Some older adolescents feel they should be involved in all decisions, even if they are *'life or death'* (230, 238), although many state they would prefer to leave these decision to parents and HCPs (162, 230, 232, 236, 238, 241,

245, 247). Experiences of involvement also depend on the types of treatment decisions being made. Adolescents whose primary treatments were oral medication regimes were more involved than with other types of treatment (238). Although most adolescents feel that they should be involved in their treatment decision-making to some degree (163, 229, 230, 232, 234, 236, 237, 241, 243, 245, 247), many state a preference for taking a passive role, as they find involvement to be boring or unnecessary, and prefer to be represented by their parent who they feel would act in their best interest (102, 229, 230, 234, 236, 238, 239, 241, 247).

2.4.4.2 Power dynamics and involvement in the decision-making process (n=26): 'Because if it's about me I should be part of it'

Adolescents value being able to choose their level of involvement (241). However, they generally see parents and HCPs as having this control, and look to them for validation of their role in the decision-making process (226, 227, 229, 232, 236). Adolescents want to be taken seriously, and feel they have a right to be involved in discussions, to have been consulted on their treatment preferences, and that these preferences are viewed as important and considered during the decision (102, 226, 228-230, 241-244, 247). They recognise that their needs are different from both adults and children, and prefer their care to be adapted as such (248). Although adolescents often do not usually want to make '*big*' or '*ultimate decisions*', they feel they should '*have a say*', and that treatment could be worse without their input (102, 162, 226, 227, 229, 230, 232, 234, 236-238, 244, 245, 248). Adolescents express a need for support and encouragement from others, in order to feel empowered to be involved in decisions that affect their own healthcare (229, 231, 232, 237-239, 245, 247).

HCPs and parents are seen as the gatekeepers, controlling the amount and type of information exchanged (239). Adolescents describe their parents as buffers or interpreters, holding the power over what information is relayed between themselves and HCPs (102, 239, 247). Adolescents also report that parents can hinder their understanding by withholding information or by not supporting attempts to gain information, often to avoid worrying their son or daughter (102, 228, 229, 241). Most studies reveal that adolescents express a need to receive information, specifically regarding future treatment such as: length of stay in hospital, appointment times, details on treatment choices, and possible side effects (226). This is in order for

them to understand their illness and treatment in order to be involved in self-management, and to know what to expect (102, 226-230, 234-239, 241-248).

2.4.4.2.1 Perceived control

Discussions which exclude adolescents make them feel as though they need not or should not be involved (226). Providing information encourages involvement (226, 228, 229, 231, 236), and encouraging involvement allows adolescents to feel empowered and validated; as a 13-year old remarked: '*they thought I was responsible enough to make a decision and I was*' (226). Adolescents state that being provided with this type of information should be a '*normal thing to do*', that it is their body and their right to know and be involved (163, 229, 230, 232, 234, 236, 237, 241, 243, 245, 247). Adolescents feel they cannot be involved when they do not understand (229). Ellis et al (163) found that the majority of adolescent patients with partial or inadequate understanding of their diagnosis felt little or no control over their treatment decision, which was not true of those who indicate complete understanding. Language is also related to control; technical jargon is described as is confusing, and can be seen as used to exert power and limit involvement (228, 229, 234, 237, 245, 247). From accounts of adolescents' experiences, Knapp et al (238) identified lack of information about the future, poor understanding of diagnosis and/or treatment, and lack of choice between treatment options as the main barriers to involvement. Many adolescents, especially those with life limiting conditions, also state they had no control over decisions due to lack of options, that treatment '*has to be done'* (208, 226, 229, 230, 232, 236, 238, 243, 247).

2.4.4.2.2 Benefits of an equal partnership

Reported benefits of discussion and decision-making involvement include greater self-efficacy, lower decisional conflict, feeling happier, less scared, and more satisfied with decisions as well as increased appointment attendance (208, 231, 233, 236, 239). Being part of treatment discussions provides an opportunity for young people to influence their situation by learning or applying self-management skills (232). However, adolescents feel they should not have complete decisional control (239). They voice concern about making the wrong decision (208, 226, 229), and trust the HCPs and parents to '*do what's best'* (226, 229, 230, 232, 234-236, 238-241, 243-247). Concern about making the wrong decision is expressed more when there is no attempt to involve the patient in the decision-making process (227).

2.4.4.3 Mismatch between involvement preferences and experiences (n=20): 'It hurts, one feels betrayed'

Adolescents appraise their positive and negative emotional, physical, coping, and knowledge responses to having their involvement preferences met (or not met) (230, 237). When adolescents receive the desired level of information regarding their condition, they report benefits such as feeling valued, happy, less anxious, and more capable of illness management (228, 231, 237, 241, 245). They consequently report feeling prepared and less worried about undergoing operations and treatment (228). However, adolescents often report receiving insufficient information about treatment and procedures (208, 229, 232, 237). Kelsey et al (237) describe the case of an adolescent boy who experienced pain and anger after being cannulated with no explanation. Seven other studies report the emotional consequences of not receiving sufficient information or explanation, which include feelings of fear and/or frustration, as though they were forgotten and depersonalised (227-229, 237, 241-243). Dunsmore & Quine found a significant difference between the degree to which adolescents would prefer each person to be involved in treatment decisions, and the degree they actually were; nearly half of the participants stated the decisions should be a collaboration between themselves, parent and HCP, whereas a very small number perceived this to have occurred; and the majority report the HCP as making the decision alone, which was generally not seen as appropriate (232).

2.4.4.3.1 Experienced more than preferred involvement

On the other side, what is seen as too much involvement, such as receiving overly detailed information, is also reported to induce stress. Many adolescents want limited exposure to details about their condition that could be worrying and/or burdensome, which they feel they may not be able to remember (229, 234-236, 238, 241, 247, 248). Adolescents sometimes experience distress from the pressure of being involved in decision-making, particularly when their treatment preferences do not coincide with those of their parents (241). Studies which compared adolescent decisions and the factors affecting their choices, such as influences and values, with those of their parents frequently found disagreement between the two parties (162, 226, 229, 230, 232, 240). This incongruity increases significantly with patient age (162). Parents and adolescents also report adolescent symptom severity and overall wellbeing differently (229).

Adolescents report feeling annoyed when HCPs address their parents as though the adolescents were not in the room (228, 232, 235, 237, 245, 247). They often feel excluded from discussions and ignored, with questions and explanation directed only at parents (226, 236, 238). They report HCPs requesting to speak to parents alone, which caused worry about a poor prognosis (229, 236, 241). Some adolescents observed that HCPs would ask them questions which they felt were 'tokenistic', or in turn ask the parents the same question, which made them feel as though their responses were not valued (228, 229). Adolescents report feeling excluded from the decision-making process or that their treatment preferences were not considered (229). They also feel that parents inhibit attempts to participate by withholding information or answering questions on their behalf (229). At times, adolescents report that they are not as involved as they would prefer because they feel rushed during consultations, and fear they may inconvenience HCPs by querying decisions or asking for more information (229). When adolescents feel uninvolved in discussions and decisions, many report negative emotions such as feeling powerless, rejected, disappointed, confused, angry, and betrayed (226, 229, 236-238, 241).

2.5. Discussion

2.5.1 Summary of findings in context of the intervention

Gaining an understanding of adolescent preferences and experiences in relation to involvement in long-term healthcare discussions and decision-making is essential to inform the development of an intervention for SDM involvement. Although studies were diverse in terms of design and samples, the results were comparable, which allowed for the development of overarching themes.

Preferences between and within each individual can vary and evolve over time. Preferences can depend on decision type and current health status. These findings reflect previous research around healthcare provision to adolescents and adults with LTCs (154, 253, 254), and highlight the need for HCPs to take an individual and flexible approach to involving adolescent patients. Involvement preferences commonly go unmet, which adversely affects adolescents' wellbeing, and their perceived ability to manage their condition. This further strengthens the argument for an individualised approach, where HCPs assess adolescents' involvement role

preferences in the decision-making at each clinical encounter in order to avoid the negative consequences associated with the mismatch between preferences and experiences. An intervention aiming to prepare and support adolescents' involvement in SDM could clarify that adolescents can be involved, but only to the extent they wish to do so. The intervention could also look at how to address concerns of adolescents with LTCs around being involved in the decision-making process, such as fears around making the "wrong" decision.

Findings from this review reveal that adolescents often feel they lack sufficient knowledge to be involved in decisions about their healthcare, and frequently report that there is no real choice. The first step of Elwyn et al's (100, 255) three talk model of SDM (team talk) involves drawing the patient's attention to the existence of healthcare options, and the importance of working as a partnership to make a choice. Provision of adequate information regarding diagnosis and treatment options, and ensuring patient understanding of the information are an essential elements of SDM (99). An intervention aimed at adolescents with LTCs in general as opposed to a specific condition would not be able to provide condition or option specific information, however, it could provide adolescents with LTCs with tools to collect the necessary information from members of their clinical teams. Nonetheless, it has been suggested that provision of information, or knowledge alone, is not necessarily enough to promote involvement in SDM (256). Patients also need to be provided with the opportunity to participate, and have confidence in their own knowledge and ability to be involved in the decision-making process (256). In developing an intervention aiming to prepare and support adolescents' involvement, it will be important to look at how to provide this opportunity and improve adolescents' self-efficacy.

The core finding that adolescents exert little control over their level of involvement is consistent with previous research on children's participation in consultations and decision-making within the healthcare setting (143). Adolescents look to others to validate and encourage involvement. Support and guidance from others has been well documented as a motivator for adolescent behaviour (257, 258). However, adolescents with LTCs often feel ignored or left out of discussions, which gives them the impression that their views are not important. They are often delegated a passive role during consultations, which does not represent the role they need to play in their

self-management, and they generally feel they should be involved in their healthcare decision-making to some degree. An intervention to support SDM should promote involvement by affirming the value and benefits of adolescent participation, and that involvement is encouraged by clinical team members.

Parents may impede opportunities to participate in decision-making by obstructing the exchange of information between adolescents with LTCs and HCPs. Parents of children with LTCs expect to participate in SDM (259), but can find it difficult to relinquish control over their child's LTC for fear of poor health outcomes (260). Lack of parental support for their child's involvement, and attempt to control the information the adolescent receives may be also attributed to parents' protectiveness (154, 261). This can be particularly troublesome as parents' treatment choices and values do not always coincide with those of their child (162). Interventions which support SDM have been found to increase values congruence between child and parent, as well as child satisfaction with the decision-making process (152). When adolescents do not participate in discussions, important input that can contribute to the formation of a suitable self-management plan, which is concordant with patient values, is not being considered. The 'three-talk' model for SDM includes 'deliberation', which outlines the importance of exploring patients' reactions to the information regarding their options in line with their own values and preferences (100, 255). An intervention to improve SDM with adolescents with LTCs should look at how to assist parents to support their child's involvement.

2.5.2 Strengths and limitations

One of the strengths of this review is the inclusion of qualitative, quantitative and mixed-methods research. By acknowledging research from a variety of methodological approaches, a more complete overview of the current evidence can be provided. In addition, this review was conducted according to recognised systematic review standards (262).

Involving two researchers to systematically searching for qualifying papers separately helps to minimise selection bias or error, and complies with the Cochrane Handbook for Systematic Reviews (262). Two reviewers who think differently on the topic area can encourage diverse viewpoints, which can challenge the others' perspectives, leading to constructive discourse, unpicking the key aspect of papers

which may stand at the boarder of inclusion, thus ensuring the criteria is thoroughly considered and discussed. Although VS and I were working in the same division at Cardiff University, her main area of research related to ethical considerations and consent to research. However, involving a second researcher from a different research background may also lead to disagreements over factors, such as procedures or semantics, which can be difficult to resolve and reach a consensus. Through discussions around disagreements over qualifying papers we found that we held differing views around what constituted healthcare decision-making, leading to clarification of the term. In these cases, a third reviewer was particularly useful to facilitate these discussions and, in the end, consensus was reached in all cases.

Due to limited resources, only English language articles were included in the synthesis. With limited literature available, studies with some non-adolescent and acutely ill participant samples were also included, which can cause difficulty in ascertaining the studies' representativeness of adolescents with LTCs in general. However, there were no distinct differences in the findings of the papers which also include participants with acute illness.

Although this systematic review included grey literature in the form of a report from the Institute for Children's Health Policy in Florida, I did not search for or include unpublished content such as social media posts and blogs including Facebook, Snapchat, or Instagram. Social media platforms can facilitate the forming of communities engaging in discussions and sharing knowledge online, reaching large segments of the population. It could be particularly useful for accessing views of hard to read populations. Approximately 70% of adolescents in the UK have some form of online social media account, with 53% spending between one and three house on social networking per normal school day (263). However, there are ethical concerns around using data for research purpose to which the person posting the information has not specifically consented, even if they have chosen to make the data publicly available. Particularly for under 16s, in which case parental consent to participate is required. Social media users may not be aware of the public nature of their data and users' comprehension of privacy literacy is often limited (264). Furthermore, the public, liberal nature of online platforms limits the reliability of the content. Best practice guidelines to assist researchers in using qualitative data derived from social media platforms, such as Facebook, are also lacking (265).

No alerts were set up to keep updated on the literature relating to the systematic search. This would have been useful to ensure that I was aware of all relevant new research and that the most recent qualifying studies were included in the chapter discussion. However, the search was rerun in September 2019 and again in November 2020, with the dates filtered so that the results would only include papers published since the previous search.

The nature of the research methods produced largely retrospective accounts of experiences which took place weeks, months, even years prior to the study. However, the narrative synthesis of participants' accounts provides insight into the adolescents' stories, including their realities around decision-making preferences and experiences. By only including adolescent generated data, this review attempts to tell the story of the adolescent from their perspective, which, as mentioned before, is often underrepresented in SDM research in paediatrics.

Ten of the 27 reports included a sample of adolescents with cancer. Unlike many LTCs, cancer has the possibility of being cured, and the focus is therefore generally on curative as opposed to management decision-making. The seriousness of the condition and, consequently, the nature of the clinical decisions involved, perhaps decreases the likelihood of clinical equipoise, and may lessen opportunity for patient involvement in SDM. Although other studies include a sample of participants with various LTCs, only one (226) compared involvement level between the two conditions. In the exemplar study, participants who had a condition with less serious outcome possibilities reported having more involvement than those with a potentially life-limiting condition (226). Although this particular study had a small sample size, an association between a more serious prognosis and less patient involvement in decision-making have been reported in adults with LTCs (266). The lack of comparisons, and variability of LTCs across the studies included in this review limits the ability to make generalisations about all adolescents with LTCs.

2.5.3 Implications for further research

Further research is necessary to establish whether a connection between adolescent preferences/experiences and LTC characteristics, such as seriousness of complications, exists. Therefore, in the exploratory chapter (Chapter 4), I will attempt to recruit and interview adolescent participants with a range of LTCs with varying

types of management options and severity of condition-related complications. This will help establish whether the findings of this review are likely to be consistent and relevant for adolescents with a variety of conditions.

Due to the limited body of research around the involvement of the population of interest in SDM, this chapter explored the perspectives of adolescents with LTCs around involvement in decision-making. Therefore, Chapter 4 will look at adolescent attitudes towards SDM, including possible barriers and facilitators. As this chapter identified a mismatch between involvement preferences and experiences of adolescents with LTCs, Chapter 4 will also focus on possible reasons for this reported mismatch.

2.5.4 Implications for practice

Findings suggest that parents and HCPs may be limiting adolescent involvement by withholding information, and not providing opportunities. Adolescents report a high level of trust in HCP expertise and may not acknowledge their own capability and potential contribution to the decision-making process. Current recommendations state that adolescents should be informed as fully as their developmental level allows, as soon as possible, and that involvement in discussions and decision-making should be encouraged and supported (267). Research shows that adolescents with LTCs benefit from SDM; it can improve their wellbeing, and potentially improve condition management and reduce absence due to illness (114, 268).

HCPs most often indicate that SDM is their usual approach to decisions with adolescents with LTCs (269), although other studies report that this is not the case in real-life practice (143, 270). HCPs were found to often provide more detailed information about their preferred option with less information about other options, and minimal elicitation of preferences or treatment goals (269, 270). HCPs may therefore need additional support, such as SDM skills training, in order for effective SDM to take place in line with the current models (99, 100, 255) tailored for communication with an adolescent population (271). In adult care, current SDM training courses for HCPs vary widely in delivery, and evidence of their effectiveness is sparse (272). It is suggested that providing HCPs with learning materials and decision aids would be helpful (272).

Adopting a flexible and individualised approach would enable adolescents to participate in a way that fits with their preferences, needs, and values. Striving to involve adolescents with LTCs beyond their preferences can lead to distress and confusion (154). Adolescents might be asserting control by opting out of involvement (154), however, effective SDM involves fully informing patients about what involvement means, and why their contribution of values and preferences for treatment are important (100, 255). SDM may be particularly important during adolescence, as this is a time when children are sensitive to authoritarian treatment (273). These patients are at a critical time where they will be transitioning, or already have transitioned to adult services when encouraging and supporting communication and involvement is crucial (274). In future, the parent may not always be a part of the consultation, particularly in instances when adolescents with LTCs move away, for example to attend university. It could be useful for adolescents to gain experience seeing their HCPs alone.

2.5.5 Research published since this review

Since the systematic search was initially conducted in 2017, interest and evidence base in the research area of SDM with adolescents with LTCs has expanded. Thirteen additional published works meeting the inclusion criteria have been identified between March 2017 and November 2020 (144, 151, 155, 268, 275-283) (Table 7). Unlike the papers included in the systematic review, many of these additional papers focused on preferences and experiences of SDM rather than healthcare decision-making involvement (144, 268, 277, 278, 280, 281). This likely represents a growing interest in SDM with adolescents with LTCs, which had previously been underexplored.

As found in the systematic review presented in this chapter, the more recently published studies reported that adolescents generally desired to receive information about options and be involved in discussions and decision-making about their healthcare, and would often prefer larger roles in these processes than they have experienced (151, 275-277, 279, 283, 284). Adolescents with LTCs stated that being involved in discussions about treatment helped to feel less scared, improved decision-making confidence, and made them feel empowered (144, 155). In line with the review findings, diverse participant preferences for participation in the decision-making process were reported (151, 155, 275-278, 282, 283). In addition, as found in

the review, preferences can vary over time and depend on the type of decision, with a larger preference for involvement for "smaller" decisions and as adolescents become experienced with their condition (155). However, not all patients agreed on what constitutes a "big" or "small" decision (155).

Adolescents with LTCs reported needing to have enough information to be involved in discussions, often turning to the internet as an information source, however, some patients preferred only to receive information on a "need to know" basis (155). In addition, adolescents stated different levels of awareness regarding involvement in decision-making, citing not knowing that they can be involved as a barrier key to SDM (144). Although adolescents with LTCs often turned to their parents for support with decision-making, particularly when they are feeling unwell (144, 155, 282), attitudes towards options and perceptions of SDM with HCPs may differ and should be considered separately (281, 282). This strengthens the above argument for consideration of patients' preferences for SDM involvement, and it is recommended that HCPs should assess this on an individual basis (277, 281). In addition, adolescents with LTCs should be offered the opportunities to see HCPs alone to discuss confidential matters (282). Adolescents with LTCs suggested that involvement in healthcare decision-making should begin early and evolve over time (151, 155, 277, 282).

Reports of incongruity between adolescent involvement preferences and experiences persist, particularly for younger adolescents, and those who hold more passive roles (151, 276, 277, 279, 282, 283). Mack and colleagues, who looked at decision-making preferences and experiences of adolescents with cancer, reported that the majority of participants wanted to share decisions with the oncologists, which did not differ by age (276). However many did not experience their preferred roles, with around half (51%) wanting their parents to limit their involvement (276). Nearly a quarter (24%) of the participants experienced regret about initial decisions, which was found to be related to feeling uninformed about options, unclear about personal values, and unsupported in decision-making (276). Stegenga and colleagues reported that 41% adolescent participants with cancer felt excluded from information or involvement in discussions about stem cell transplants, with no difference between gender, although younger age was associated with higher likelihood of

perception of exclusion (283). This demonstrates the importance of the three stages (team talk, option talk, decision talk) for SDM to occur (100, 255).

One study, which aimed to evaluate an SDM intervention for adolescents with juvenile idiopathic arthritis, reported several benefits, with the intervention compared to control group showing significantly increased involvement in decision-making, higher adherence to treatment regimes, improved patient-reported outcomes (e.g. quality of life), and fewer absences from school (268). This was a paper decision support tool developed by researchers following the guiding principles of the Ottawa Decision Support Framework (112), which contained visual aids, such as pictures and diagrams. Other reported benefits of adolescent involvement in SDM include decreased decisional conflict and improved adolescent-parent dyad agreement around healthcare options (280). However, SDM with adolescents with LTCs continues to be limited in practice (151, 268, 278, 279, 284). For example just over half (51%) of the 15 to 17-year old participants with cancer reported being told what their treatment would be without any offer of other options (276).

The additional papers add further exploration of the SDM components, including presentation of treatment options and elicitation of patient values and preferences (268, 278, 284). Robert and colleagues (275) reiterated that information provision is not enough to ensure the involvement of adolescents with LTCs in the decision process. Barber et al (278) reported that adolescents with LTCs often lack awareness of the decision to be made and all possible options, and experience insufficient of elicitation of values and preferences, which were reported as barriers to SDM. Hayes and colleagues (144) also found that adolescents reported a lack of awareness of existing options as well clinicians' listening and communication skills as barriers to SDM

These papers further emphasise the need for SDM interventions, which focus on the key SDM components. Furthermore, Koller (151) reported that preparation for decision-making is essential for adolescent participation.

Table 7. Table of qualifying studies published since the review

Study: Author, year, Country	Study aims	Design	Patient population characteristics	Health Condition(s)	Patient Age range	Definition of involvement
Barber *et al,* 2019 (278) **United Kingdom**	To determine the extent to which the current care pathway in hypodontia promotes SDM	Qualitative: individual interviews	N=8 40% female	Hypodontia	12 to 16	SDM: A collaborative process in which clinicians support patients to make decisions about their own healthcare given their individual circumstances.
El Miedany, 2019 (268) **Egypt**	To develop and evaluate a SDM intervention for children with juvenile idiopathic arthritis	Quantitative: pilot RCT	N=189 57% female	Juvenile idiopathic arthritis	6 to 15	SDM: informed, meaningful, and collaborative discussions between patient and HCP, putting the patient at the centre of decisions about their own treatment and care.
Hayes et al., 2019 (144) **United Kingdom**	To explore the barriers and facilitators to SDM from adolescents' perspectives	Qualitative: individual interviews	N=9 100% female	Internalising difficulty	12 to 17	SDM: Actively involved in treatment decisions.
Jordan et al., 2019 (279) **United Kingdom**	To explore perceptions of adolescents with LTCs around barriers and facilitators to involvement in SDM	Qualitative: Individual interviews	N= 19 74% female	Various LTCs	13 to 19	SDM: Receiving information about options and being involved in discussions around the options including risks and benefits in line with patients' values and preferences in order to reach a shared decision.
Kebbe et al., 2019 (282) **Canada**	To explore adolescents' perspectives on their involvement in decision-making for weight management.	Qualitative: individual interviews	N=19 58% female	Obesity	13 to 17	Patient participation in the decision-making process.
Koller, 2017 (151) **Canada**	To examine how children with LTCs view healthcare education and decision-making	Qualitative: individual interviews	N=7 Male/female ratio not reported	Various LTCs	5 to 18	Healthcare education and participation in decisions-making.
Lawson et al., 2020 (280) **Canada**	To evaluate decision coaching using a patient decision aid for helping adolescents with type 1 diabetes and parents decide about insulin delivery method	Quantitative: Pre/post design	N=45 44% female	Type 1 diabetes	6 to 17	SDM: patients and families together with clinicians discussing the best available evidence about options and patients' informed preferences to make the best treatment decision for the child
MacDonald et al., 2019 (281) **Canada**	To assess the level of decisional conflict and SDM experienced by adolescents when considering elective adenotonsillectomy.	Quantitative: cohort study	N= 53 53% female	sleep-disordered breathing and/or recurrent/chronic pharyngotonsillitis	9 to 16	SDM: collaborative process involves the clinician sharing the most up-to-date evidence-based information, while the patient/family members share personal values and preferences that could influence the decision.

Mack et al., 2019 (276) United States	To evaluate cancer treatment decision-making among adolescents, including decisional engagement and regret.	Quantitative: cross sectional surveys	N=203 Male/female ratio not reported	Cancer	15 to 29	Decision-making involvement including the extent to which patients are satisfied with or regret decisions about care.
Pyke-Grimm et al., 2020 (155) United States	To explore the involvement of adolescents, aged 15 to 20 years, in cancer treatment decision making	Qualitative: Individual interviews	26 38% female	Cancer	15 to 20	Participation in treatment decision-making.
Robertson et al., 2019 (275) Australia	To explore adolescents' views and perceptions of making decisions in paediatric oncology	Qualitative: Individual interviews	N=5 20% female	Cancer	11 to 15	SDM – Involves introducing choice, describing options, and ensuring patients are well informed and included in the decisions.
Stegenga et al., 2018 (283) United States	To learn about perceived access to transplant information and involvement in decision making among adolescents.	Qualitative: Individual interviews	N=17 Male/female ratio not reported	Cancer	10 to 18	Access to treatment information and engagement in treatment decision making
Wogden et al., 2019 (277) United Kingdom	To understand the involvement of adolescents with cleft lip and/or palate in decisions about elective surgeries and treatments.	Qualitative: Individual interviews	11 73% female	Cleft lip and/or palate	12 to 25	SDM: a person-centred approach in which service users actively engage in decisions surrounding their health car

2.5.6 Critique of studies reporting SDM interventions

A total of ten papers have been identified describing six distinct interventions targeted at promoting SDM with adolescents with LTCs and HCPs about their healthcare. Two studies included in the initial systematic review and thematic synthesis aimed to evaluate SDM interventions, including a printed decision guide and decision coach for insulin delivery options for type 1 diabetes (233) and decision aid documents for treatments for neuromuscular sclerosis and environmental allergies (208). Among papers meeting the inclusion/exclusion criteria published since the systematic search conducted in 2017, two qualifying studies described SDM interventions, including an illustrated decision aid for children with juvenile idiopathic arthritis and testing of the aforementioned printed decision guide and decision coach for insulin delivery options for type 1 diabetes, which had been amended slightly as a result of the decision coach feedback (268, 280).

Five further papers reporting three different SDM interventions targeted at adolescents with LTCs were identified, although they did not meet the inclusion criteria for the systematic review as none reported adolescents' preferences nor experiences of involvement in healthcare decision-making with HCPs. These additional interventions include coloured cards with visuals to facilitate SDM with adolescents with juvenile idiopathic arthritis (117, 207); a pre-consultation guide in the form of an A5 booklet to promote the participation of young people with asthma in review consultations (164, 209); and an educational video to motivate adolescents with asthma to be more involved during medical visits (206).

Of the ten papers describing SDM interventions for adolescents with LTCs, three outlined the intervention development, all of which included adolescents in the process (164, 206, 207). However, none of the other papers mentioned involving adolescents in the development process. Only two of the interventions were described as using theoretical models to guide the development which were the Health Action Process Approach (164, 209) and Social Cognitive Theory (206). As the MRC guidance stipulates: "*Best practice is to develop interventions systematically, using the best available evidence and appropriate theory*" (169).

One paper outlined a qualitative evaluation of the intervention, which found the intervention to be described as reassuring and supportive by adolescents with

asthma, but did not report whether the adolescents felt the intervention would increase involvement during consultations. Four of the papers described quantitative testing of interventions (117, 208, 233, 268, 280). Outcomes of the SDM interventions included improvement in treatment adherence (208, 268), improved health outcomes (268), increased patient involvement during consultations (268), and decreased decisional conflict (208, 280). However, only one of these studies was not a pilot and/or feasibility test (268) and three of the studies included a pretest-posttest test design with no control group (208, 233, 280). Only one paper described patients' perceived barriers and facilitators to SDM, and how the intervention aimed to address these (206). One study found no differences to SDM outcome measures with or without the intervention (117).

All the SDM interventions described have been targeted at adolescents with specific conditions, with many tailored to specific decisions. While these have the advantage of including condition, option and preference specific information, there has been no identified intervention which could be used for all LTCs for any decision. As it could be near impossible to develop a specific intervention for every LTC and decisional situation, there is a need for a more generic intervention which could be applied in a variety of circumstances so that no patients are left out.

2.5.7 Conclusion

Adolescents with LTCs want their views to be taken seriously and to feel they have the right to be involved in the decision-making about their healthcare. Adolescents' preferences for involvement can vary within and between individuals, and are often dependent on factors such as timing, decision type, acute wellness, and age for younger adolescents. Experiences of involvement also vary and tend to evolve over time, however, they often do not match adolescents' preferences. Adolescents with LTCs often want larger roles than they occupy. Failure to involve adolescents in the decision-making process can cause feelings of exclusion and neglect. However, striving to make them fully informed and involved may also be counter to their preferred (sometimes 'passive') way of being involved in decisions, which in turn may trigger anxiety and distress.

Adolescents need to feel ready to receive information about their condition, particularly if the information may be distressing. As adolescents with LTCs obtain

more information about their condition and healthcare options, they are more likely to be involved in the decision-making process. Other factors which influences the decision-making process, are the roles of the parents and HCPs. Adults are seen to have jurisdiction over the decision-making process, and to be the ones who control whether and to what extent adolescents are involved. HCPs need to take an individual and flexible approach to assessing adolescents' preferences for decision-making involvement including information provision.

The findings from this chapter illustrate the need for, and will be used to inform the development of, an intervention to prepare and support the involvement of adolescents with all types of LTCs in SDM. The following chapter will explore relevant theoretical models which may be effective in explaining the participation (or lack thereof) of adolescents with LTC in SDM, as well as approaches to intervention development. Later chapters will look at filling the gaps identified in this review, including perceptions of adolescents with LTCs around SDM, including factors which may enable or prevent involvement.

Chapter 3: A critical evaluation of relevant models, theories, and approaches

3.1 Chapter overview

In the previous chapter, a systematic review reported the preferences and experiences of adolescents with long-term conditions (LTCs) around decision-making about their healthcare. The need for an intervention to prepare and support adolescents with LTCs to be involved in shared decision-making (SDM) was illuminated. In order to generate a platform for planning and developing the intervention, appropriate theoretical models and development approaches must be identified. By increasing awareness of the relevant theory base, the most appropriate framework(s) can be selected and used to organise and explain the data, and contribute to identifying crucial intervention components. This chapter addresses Objective 2 of this thesis, discussing a range of behaviour change theories in the context of SDM with adolescents with LTC. I will also present approaches to intervention development in this chapter.

3.2 Introduction

As outlined in Chapter 1, the Medical Research Council (MRC) framework for developing and evaluating complex behaviour change interventions highlights the importance of identifying relevant theory in order to gain an understanding of the behaviour to be targeted by the intervention, as well as the barriers to, and facilitators for that behaviour and the changes that may be expected (169). Identifying relevant theory facilitates insight into the likely processes underlying the behaviour before testing, so that the intervention content can be designed to specifically address these processes, and suitable evaluation measures can be selected to test for intervention efficacy. However, Ogden (285) comments that there is substantial variability between patients and theoretical models, and that there are consistent gaps; for instance between patient intention and their behaviour, or between healthcare professionals' (HCPs') beliefs and their training. It has also been argued that interventions should not be developed based on one theory alone, rather they should research the target population's psychology (286). This enables the researcher to move from one theoretical perspective to a more flexible integration of

theories. By identifying a range of theories, researchers are able to assess the value of each in relation to the behaviour, population, and context.

In the previous chapter, I identified that the voice of adolescents with LTCs has been under-represented, both during consultations and in SDM research (114, 204). I will therefore attempt to guide the entire process of intervention development using the adolescents' narratives, by prioritising and incorporating their perspectives wherever possible. This is the basis of Yardley et al's Person Based Approach (200) (discussed in detail below) which complements, and can be used alongside, the MRC guidance (167). Although there is substantial overlap between the Person Based Approach and the stages of intervention development in the MRC guidance, the Person Based Approach further compartmentalises the steps to development including specific objectives (e.g., to conduct qualitative research) with increased emphasis on user-centredness. This may be particularly important when developing an intervention aimed at population who have been historically marginalised (114, 143, 204).

3.2.1 Chapter aim and objectives

The aim of this chapter is to identify relevant theory and approaches for intervention development. The objectives were to (a) critically evaluate relevant theoretical models for behaviour and behaviour change in the context of SDM with adolescents with LTC and (b) identify and evaluate approaches to intervention development, including the selection of the most appropriate approach in line with the aims of this PhD thesis.

3.3 Person-Based Approach

The Person Based Approach (200) aims to base the development of behaviour change interventions on the perspectives and lives of its target audience. It is used to evaluate and enhance feasibility and acceptability of an intervention during its earliest stages of development in an attempt to maximise the likelihood of a successful outcome. This approach involves identifying intervention components that are likely to be necessary, feasible, and salient by focusing on understanding and accommodating the perspectives of the people who will use the intervention, which is considered essential to maximizing the acceptability and effectiveness of interventions (200). Qualitative research is a core feature of the approach at the

planning and development stage, and enables developers to gain vital insights into how different people experience and implement interventions, and a framework to help developers identify the key characteristics that will make an intervention more meaningful, attractive, and useful to those who engage with it (200). From the findings from the systematic review (Chapter 2) and qualitative research exploring the narratives of adolescents with LTCs (Chapter 4), a set of guiding principles can be generated to assist in the development of the intervention. The Person Based Approach involves four stages of development and evaluation: intervention planning, design, development and evaluation of feasibility and acceptability, and Implementation and trialling (Figure 5).

Planning	Design	Development and evaluation	Implementation and trialling
Identify key behavioural issues, needs and challenges: • Synthesise prior evidence (Chapter 2) • Conduct primary qualitative research (Chapter 4)	Create guiding principles to guide intervention development: • Key intervention design objectives (Chapter 5) • Key intervention features to achieve objectives (Chapter 5)	Evaluate and optimise intervention components: • Elicit, observe and analyse user reactions to intervention elements(Chapter 6) • Iteratively modify to optimise (Chapter 6)	Evaluate in real-life context(s) and modify to improve implementation in future: • Mixed methods process analyses to identify further modifications to improve acceptability, feasibility, and effectiveness of intervention for future implementation (proposed Chapter 7)

Figure 5. Person Based Approach (200) processes outlined in this PhD thesis

3.3.1 Intervention planning

This stage is similar to the '*Development'* phase of the MRC framework (169). It involves synthesising qualitative studies of user experiences of previous interventions and carrying out qualitative research to explore user views around the targeted behaviour change and planned intervention, including perceived barriers and facilitators. This involves consultation with experts, members of the user group and other stakeholders. As discussed in Chapters 1 and 2, the body of research around SDM and interventions to improve SDM for adolescents with LTCs is limited. Furthermore, most of the pre-existing literature reports data derived from parents or healthcare professionals (HCPs), with limited representation from the adolescents.

Therefore, the systematic review aimed to synthesise the body of evidence around adolescents' involvement in healthcare decision-making, including preferences and experiences (Chapter 2). Subsequently, qualitative interviews will be used to address any information gaps in the review, with particular focus on eliciting user views surrounding perceived barriers and facilitators to SDM (Chapter 4).

3.3.2 Intervention design

The intervention design stage is another component of the *Development* phase of the MRC framework (169). This stage involves creating of a set of guiding principles which help to summarise the features of the intervention identified which are central to achieving the objectives of the intervention. Identification of the behavioural issues, needs, and challenges in stage one (planning) will inform the generation of these principles as key features of the intervention needed to achieve the objective (involvement in SDM). At this point appropriate theory can be identified and used in creating the guiding principles, as discussed in this chapter. This will allow for theoretical modelling in the form of logic model creation and mapping of behavioural determinants, which will be discussed in detail in Chapter 5.

3.3.3 Development and evaluation of feasibility and acceptability

This stage also fits with the *'Development'* phase of the MRC framework (169). It involves evaluating intervention components in detail from the perspective of those for whom the intervention is intended (adolescents with LTCs). User responses to the intervention should be prompted, observed, and analysed. In this stage, a prototype of the intervention will undergo testing in order to elicit user reactions to every element of the intervention using the think aloud technique, as well as overall impressions and feedback (Chapter 6). Reactions of those intended to deliver the intervention should also be sought (HCPs). The findings will be used to modify the intervention to optimise acceptability and feasibility from a user perspective.

3.3.4 Implementation and trialling

This stage is similar to the *Feasibility and Piloting* phase of the MRC framework (169). It involves a process evaluation of the implementation of the intervention in a real-life context to analyse mediators and moderators, such as reach, fidelity, and context effects. Mixed methods processes are used to evaluate and identify further

modifications to improve intervention acceptability, feasibility, and effectiveness for future implementation, or for use in different contexts. Effectiveness and cost effectiveness are evaluated using experimental methods (e.g., pilot RCT). Although this stage will not all fit into the remit of this PhD thesis, a protocol for a pilot RCT with embedded feasibility testing and process evaluation will be proposed in Chapter 7.

3.4 Theory in behaviour change and SDM intervention development research

As discussed in Chapter 1, the use of patient decision aids can have numerous benefits to patients including being better informed and clear about their values, and experiencing less decisional conflict (113). It was outlined that although patient decision aids can support SDM, they do not equate to SDM. There is some evidence of the effectiveness of interventions for increasing SDM with adult patients, including patient and HCP skills training (287, 288). However, a Cochrane review of 87 studies found the effects of SDM interventions to be unclear due to heterogeneity of studies and low certainty of evidence, including inadequate management of bias with limited and varied effects (103). A number of reasons could account for these findings, such as a lack of rationale for the chosen intervention and inappropriate methods used to design the interventions (289). However, it is difficult to determine reasons for ineffective interventions without a detailed description of the stages of developing the intervention and its components, and how the intervention is expected to work (290). Therefore, efforts should be made towards improving reporting of intervention development and maximising intervention effectiveness (289) which further emphasises the importance of theory, as outlined in the MRC guidance (169).

There are several reasons for using theory in intervention design. Firstly, it enables the identification of factors associated with a given behaviour and behaviour change in order for them to be appropriately targeted by the intervention (291). Techniques to change behaviour can then be selected and refined accordingly (292, 293). Secondly, theoretical mediators of the intervention can be investigated to establish how the intervention has an effect, and therefore can be refined and improved effectively (292, 293). Thirdly, theory provides a summary of knowledge around how to make behavioural changes across different populations, behaviours, and contexts.

Although the advantages of theory have been established, researchers often design behaviour change interventions without reference to theory (289). A recent systematic review evaluating SDM interventions found that only 36% studies used a theoretical framework, and in 14% of these cases the framework was not described (103). The MRC (169) framework omits guidance on the selection of appropriate theory, which can be a complicated task as there is a multitude of health behaviour and behaviour change theories. A recent scoping review identified 82 theories across the social and behaviour sciences of potential relevance to public health interventions (289). Out of the 82 theories identified, eight theories accounted for 75% of the retrieved articles describing interventions for behaviour change. These include: Health Belief Model (294), Theory of Planned Behaviour (295), / Reasoned Action Approach (296), Social Cognitive Theory (297), Social Learning Theory (298), Information–Motivation Behavioural Skills Model (299), Self-determination Theory (300), Health Action Process Approach (301) and Transtheoretical Model of Change (302). Due to extensive use of, and body of evidence around these models, these theories will all be discussed and critically evaluated in the context of the research area of this thesis (SDM with adolescents with LTCs), apart from Social Learning Theory, which was a precursor of Social Cognitive Theory. Each model is summarised in turn below (Table 8).

Table 8.Summary of theoretical models outlined in this chapter

Publication Date(s)	Theoretical Model(s)	Author(s)	Brief Description in the context of SDM with adolescents with LTCs	Criticisms
1974	**Health Belief Model**	Rosenstock et al. (294)	How adolescents with LTC evaluate the seriousness of the outcomes resulting from not being involved in SDM, alongside their perceived susceptibility to these outcomes will affect the likelihood of SDM occurring.	The model does not take into consideration adolescents' emotions, social norms, or access to information.
1977 1986	**Social Learning Theory** **Social Cognitive Theory**	Bandura (297, 298)	People set goals for themselves and direct their behaviour accordingly. Adolescents with LTCs need to be motivated to be involved in SDM for it occur. Motivation depends on self-efficacy around involvement in SDM along with expectations of SDM outcomes, including how adolescents feel others would perceive the behaviour, and perceived barriers and facilitators to involvement	Goals may not necessarily result in behaviour. The model assumes that changes to the environment will automatically result in behavioural changes, and does not take into consideration the inner traits, including emotion
1985 2007	**Theory of Planned Behaviour** **Reasoned Action Approach**	Ajzen (295) Fishbein and Ajzen (296)	Adolescents' attitude towards SDM (e.g., is it positive or negative?), along with perceived social norms (are others doing it and is it encouraged), and perceived behavioural control influence their intentions to be involved in SDM, resulting in SDM behaviour.	May be useful for predicting intention but not necessarily actual behaviour (intention-behaviour gap). Does not consider adolescents' emotions around the behaviour.
1997	**Transtheoretical Model of Change**	Prochaska and Velicer (302)	Adolescents with LTCs become aware of, and consider being involved in SDM, then make their way through the stages of change until the behaviour is maintained.	This model may be suited to more frequent habitual behaviour (e.g., smoking cessation). Insufficient consideration of social and environmental factors.
2000	**Self-Determination Theory**	Ryan (300)	Adolescents with LTCs need to feel confident that they have the skills to be involved in SDM, that they have control over the extent to which they are involved, and that being involved is both a normal thing to do, and desired by others (e.g., parents and HCPs) in order for SDM to occur.	Only recognises three needs (competence, autonomy, and relatedness). Evidence for the theory's effectiveness in predicting behaviour is limited compared to other theoretical models
2003	**The Information-Motivation-Behavioural Skills Model**	Fisher and Harman (299)	Involvement in SDM depends on the extent adolescents with LTCs are informed of how to be involved, feel motivated, and have the skills to be involved. Motivation depends on adolescents' perceived outcomes of SDM and perceptions around norms and approval of others. Skills include self-efficacy and actual ability	Assumes that the individual has complete control over their engagement in the behaviour. May be best at predicting behaviour that does not rely on other parties.
2008	**Health Action Process Approach**	Schwarzer et al. (301)	Adolescents with LTCs will have the intention to be involved in SDM if they perceive the behaviour to reduce risks and provide benefits. Intention becomes action if they know exactly how to be involved, feel capable of being involved and that their involvement will be supported by others (e.g., parents and HCPs).	Only some components of the model have been found to effectively predict behaviour (self-efficacy). Does not adequately consider the roles of social and environmental factors (e.g., norms)

3.4.1 Health Belief Model

The Health Belief Model (294) was developed in the 1950s to explain and predict risk-related, as well as health promotion behaviours, particularly in regards to engagement in health services. Health Beliefs and the Health Belief Model have been able to effectively predict help-seeking behaviour in adolescents with long-term health issues (303). The core concept of the model is how an individual perceives a personal health threat, combined with their perception of effectiveness of the intervention or treatment, will predict the likelihood of the behaviour being pursued. It is hypothesized that health-related behaviour is connected to three factors which are firstly, sufficient motivation or concern to make health issues relevant; secondly, the belief that they are vulnerable or susceptible to health problems; and finally, evaluation of the perceived barriers and the benefits around said behaviour (294). Cues to action are also included in the model, which could include social cues such as prompts or encouragement from a peer, family member, or HCP or system-related cues such as campaigns, for example The MAGIC programme's *Ask 3 Questions* Campaign where patients are prompted to ask HCPs: "*What are my options*", "*What are the benefits and possible risks?*", and "*How likely are these risks and benefits?*" (304). The Health Belief Model also suggests that these constructs are influenced by demographic variables such as age and gender, as well as structural variables such as knowledge (Figure 6).
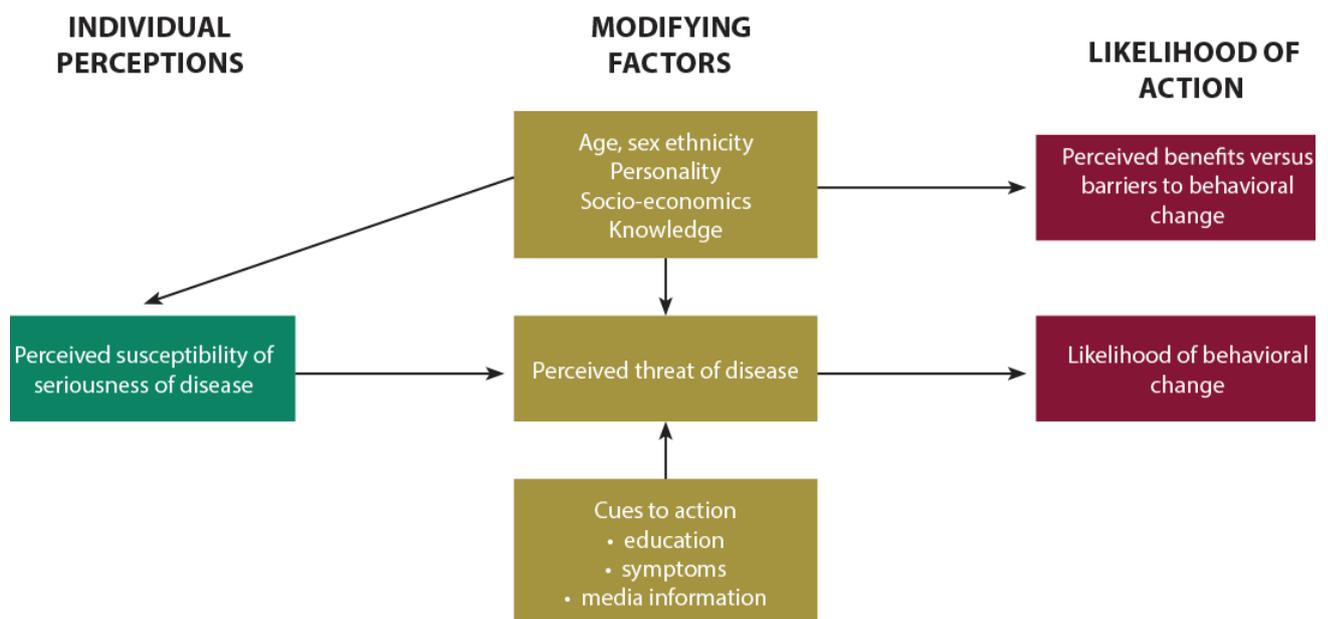
Figure 6. Health Belief Model (294)

In line with the Health Belief Model, benefits and barriers have been found to be important predictors of adolescents' proactive health behaviour, with perceived benefits being the strongest predictor, although no relation was found between perceived susceptibility and severity and behaviour or intention (303). However, the Health Belief Model focuses on the outcome of a particular behaviour, and the perceived seriousness and susceptibility around that particular outcome. There is evidence to suggest that SDM can improve knowledge and reduce decisional conflict in adult populations (113) as well as parents (114), and some evidence that decision aids may reduce decisional conflict for adolescents (119, 121, 305), however one study found no difference (306). Evidence of outcomes of interventions which aim to engage adolescents in consultations about their long-term conditions is very limited (307), therefore outcomes of SDM in this population are generally unknown. Even with the outcome of reduced decisional conflict, according to Health Belief Model, the adolescent behaviour would be motivated by this outcome, which may not be viewed as sufficiently serious. Furthermore, the Health Belief Model does not include emotions such as fear or worry, which are commonly experienced by adolescents with LTCs particularly around information provision which is central to SDM (17, 229, 234, 235, 308). The original model did not consider self-efficacy, which is particularly important as adolescents' confidence in their ability to participate in aspects of SDM, such as retain information and make "good" decisions, can affect their attitudes around involvement (208, 226, 309). However, self-efficacy was added to the model in the mid-1980s (294).The Health Belief Model also does not account for social norms, a potentially important barrier to SDM where patients' presumptions of the 'normal', expected patient role can lead to passivity and expectations that clinicians make decisions (256). Finally, the Health Belief Model assumes that everyone has access to the same information around the health behaviour and the possible outcomes resulting from the given behaviour.

3.4.2 Theory of Planned Behaviour/ Reasoned Action Approach

The Theory of Planned Behaviour (295) developed in the 1980s, which was later refined as the Reasoned Action Approach in 2007 (296), has been used extensively to predict adolescent intention and health behaviour (310-312). According to the Theory of Planned Behaviour, action is determined by intention and perceived behavioural control, or confidence that the behaviour can be performed (295) (Figure

7). Intention represents the motivation to engage in a behaviour, and is determined by attitudes towards the behaviour (e.g., personal evaluations of SDM) and social norms (e.g., whether they feel that others such as parents, HCPs and peers want them to engage in SDM, and perceive it as normal) and perceived behavioural control (perception around ability to be involved in the decision-making process). The Theory of Planned Behaviour has been employed in the development of decision aids (288, 313), and was found to be a good predictor of intention around decision-making (313).
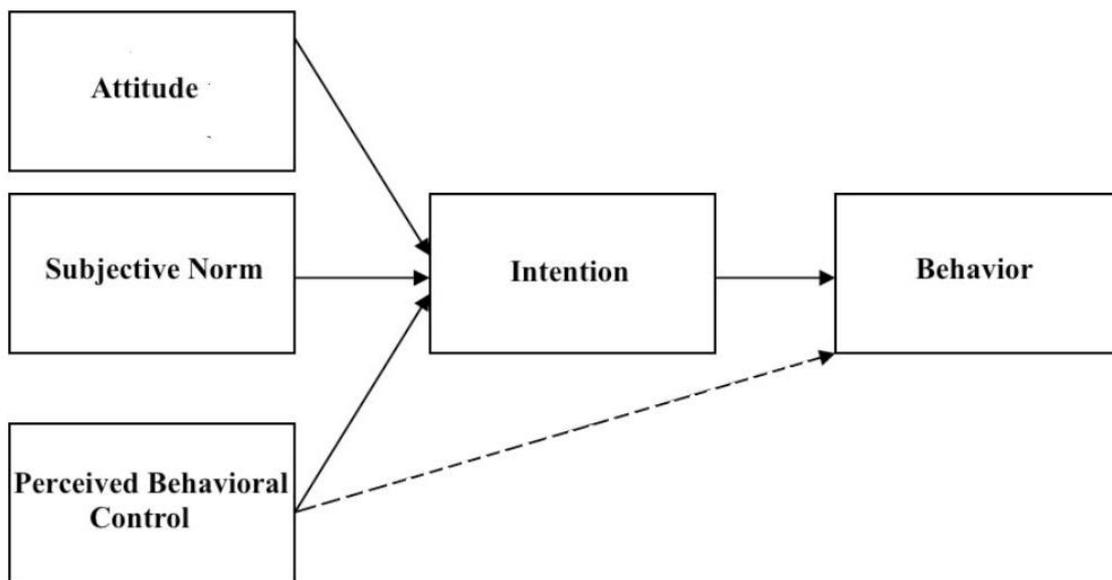
Figure 7. Theory of Planned Behaviour (295)

The Reasoned Action Approach differs from the Theory of Planned Behaviour in how it distinguishes pairs of sub-components of attitudes, perceived norms, and perceived behavioural control as predictors of intention and action (296). Attitude is characterised by experiential and instrumental attitudes (i.e. anticipated positive or negative consequences vs perceived positive or negative consequences); perceived norm by injunctive and descriptive norms (i.e. perceptions concerning what should or ought to be done versus perceptions that others are or are not performing the behaviour in question); and perceived behavioural control by capacity and actual control (i.e. the belief that one can, is able to, or is capable of, performing the behaviour, similar to self-efficacy vs actual relevant skills and abilities) (Figure 8).
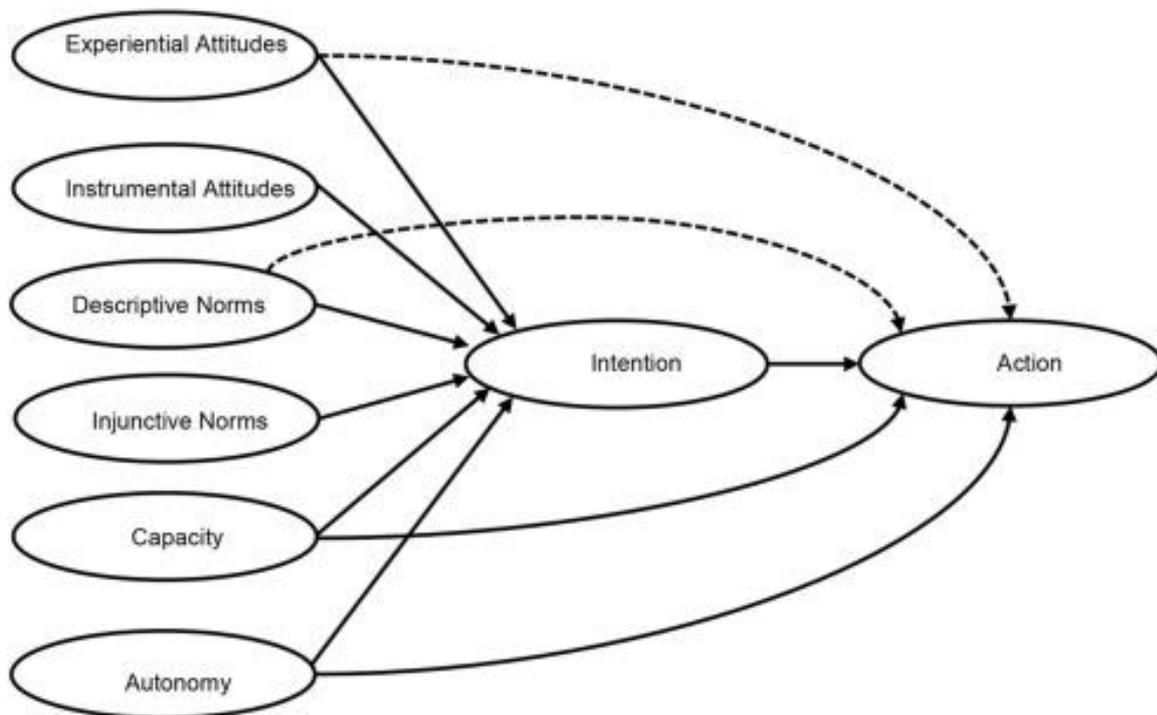
Figure 8. Reasoned Action Approach (296)

So, according to the Theory of Planned Behaviour and Reasoned Action Approach, the performance of a health behaviour is governed by the strength of intention to perform the behaviour. Therefore, if applied to SDM with adolescents with LTCs, the strength of adolescents' intentions to be involved in the decision-making process is influenced by behavioural beliefs about the consequences of being involved, normative beliefs such as parents and HCPs supporting involvement and perceiving that other adolescents with LTCs are involved in SDM, that it is normal for them to do; and control beliefs including difficulty around processing information, being involved in discussions, and decision-making. For example, if an adolescent with a LTC believes that: SDM will benefit them by resulting in a treatment plan which is best suited to them (behavioural beliefs); that HCPs and their parents want them to be involved and support their involvement (normative beliefs); and that they have the capacity to be involved in the discussions and make a "good" decision (control beliefs), their intention to be involved in the decision-making process will be high and thus most likely result in SDM.

In contrast to the Health Belief Model, the Theory of Planned Behaviour and Reasoned Action Approach attempt to address the problem of social and environmental factors in the form of normative beliefs. However, a meta-analysis of

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the Theory of Planned Behaviour in relation to a number of health behaviours found that although the Theory of Planned Behaviour provided strong predictions of intention, prediction of actual behaviour was significantly weaker (314). In addition, intentions are not actually effective when predicting adolescent behaviour (315). This has been referred to in the literature as the "intention-behaviour gap"(316). Furthermore, a decision aid developed using the Theory of Planned Behaviour was not found to increase intention to be involved in SDM (288). Finally, like the Health Belief Model (294) the role of emotion is not represented in the Theory of Planned Behaviour, which, as discussed above, is important for the context of the target behaviour and population of this thesis.

3.4.3 Social Cognitive Theory

In the mid-1980s, the Social Cognitive Theory proposed that self-efficacy beliefs operate alongside goals, outcome expectations, perceived environmental impediments, and facilitators in the regulation of human health behaviour (297) (Figure 9). The model emphasises expectancies, incentives, and social cognitions. Expectancies include beliefs such as '*Involvement in SDM results in selecting the best healthcare option for the patient'*, '*If I were involved in SDM, the outcome would be positive for me'* or '*I can be involved if I want to'*. Incentives relate to the impact of the consequence of any behaviour and are closely aligned to reinforcements. The concept of incentives suggests that the behaviour is governed by its own consequences. For example, SDM would be continued if the adolescent were happy with the treatment option and felt positive about being involved in the decision. However, involvement would be stopped if the adolescent experienced decisional conflict or regret or felt that their involvement was unwanted. Finally, social cognitions reflect the individual's representation of their social world in terms of what others think about the particular behaviour. Social cognitions are a central part of the Social Cognitive Theory and reflect the individual representations of their role in the world, for example not wanting to be labelled as a 'difficult' patient, which is a known barrier to SDM in adult populations (317). The Social Cognitive Theory states that knowledge about health risks and benefits help create a desire for health behaviour change, but that the construct of self-efficacy is crucial in facilitating the change in behaviour. Therefore, according to the Social Cognitive Theory, for Adolescents with LTCs to engage in SDM it is crucial for them to have confidence in their ability to be

involved in discussions, gather sufficient information around options, and contribute to the selection of an option which is most appropriate for them.
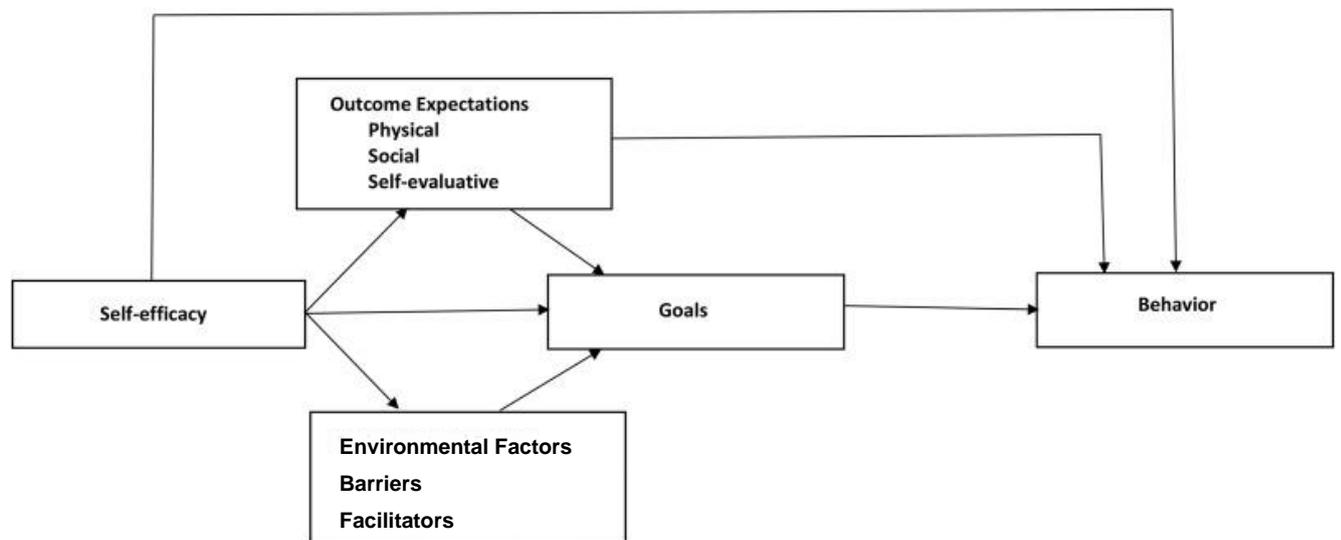
Figure 9. Social Cognitive Theory (297)

Social Cognitive Theory has been used successfully in the development of a patient targeted SDM intervention resulting improved patient question asking, patient activation and positive patient affect (318). However, the same intervention found no improvement in overall patient-centredness, meaning there was no improvement in the discussion of patient concerns (318). In adolescent populations, similar to issues with the Theory of Planned Behaviour, the Social Cognitive Theory was able to effectively explain intention, but not actual health behaviour, therefore the intention-behaviour gap is still an issue (319, 320). The Social Cognitive Theory also assumes that environmental changes (barriers and facilitators) will automatically result in changes in the individual when this may not always be the case. Although environmental changes may help alleviate some of the barriers associated with adolescent engagement in SDM, it may not be enough to individually modify behaviour. The Social Cognitive Theory omits the individual's inner traits, such as emotion, which may be a contributing factor to behaviour, particularly for the target population in this PhD. Furthermore, the theory does not seem to specify the nature of the dynamics between the individual, behaviour, and environment, and which elements may be more influential than others.

3.4.4 Transtheoretical Model of Change

The fundamental concept of the Transtheoretical Model of Change, developed in the late 1990s, is that behaviour change is most successful when behavioural strategies, referred to as processes of change, are applied at the most appropriate time (302). The Transtheoretical Model of Change proposes that a behaviour change occurs in five different stages from pre-contemplation (not planning to change within the next six months), contemplation (thinking about changing), preparation (taking steps to change), action (attempting the change) and maintenance (having changed for at least six months) (Figure 10). Although the stages are presented in a linear fashion, in reality, individuals may pass back and forth through different stages. It is proposed that individuals in the early stages of change use cognitive or experiential strategies, such as self-re-evaluation, to progress forward through the stages of change. Individuals in the later stages use behavioural processes such as helping relationships or stimulus control more frequently. As the individual progresses further through the processes of change, the cons relating to a given health behaviour should decrease whilst the pros should increase.
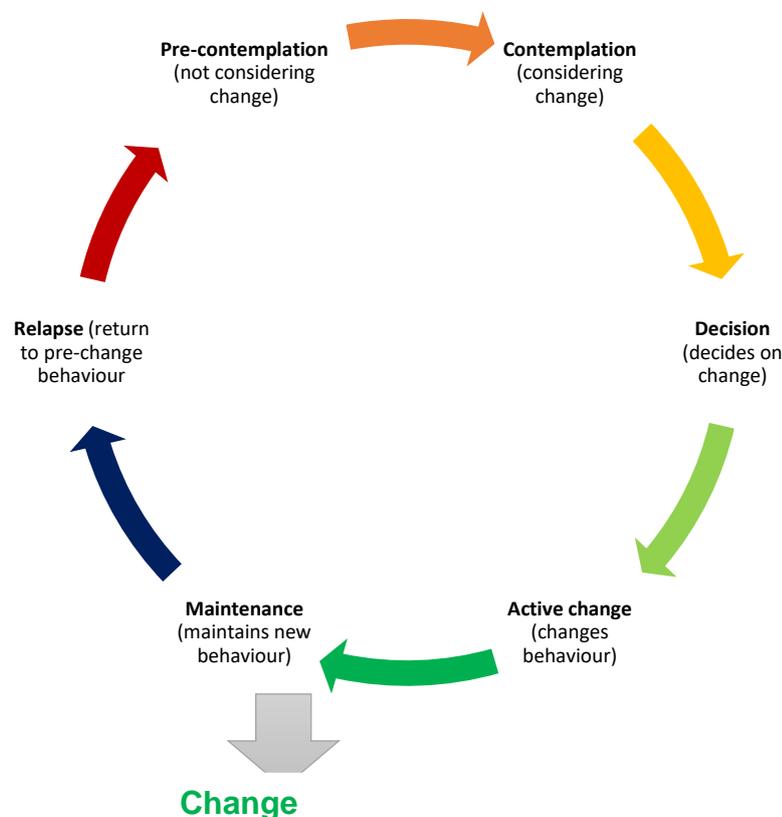
Figure 10 Adaptation of the Transtheoretical Model of Change (302)

Considering the Transtheoretical Model of Change processes as applied to SDM with adolescents with LTCs, the first stage (pre-contemplation) involves increasing awareness about SDM and improving accuracy of information about SDM (consciousness raising), experiencing, and releasing feelings about SDM and engaging in SDM (dramatic relief), and thinking that engaging in SDM would impact positively on the social environment (environmental re-evaluation). The second stage (contemplation) refers to the cognitive and affective assessments of how engaging in SDM may impact on the individual's self-image, for example feeling as an empowered and active patient when involved in SDM, and perceiving SDM as yielding a beneficial outcome. The third stage (preparation) refers to an individual's belief that they are able to overcome previous barriers to SDM (e.g., parents taking over (229)), and their commitment to acting on the behaviour, such as asking questions about options and being involved in discussions and decisions (self-deliberation). The fourth stage is the action stage and refers to the utility and availability of helping relationships, counterconditioning, reinforcement management and stimulus control. This would include the ongoing support of parents and HCPs surrounding the adolescent's involvement in SDM in order to perform the behaviour, and afterwards experiencing positive outcomes to maintain. The final stage is maintenance and involves social liberation, social, policy or environmental changes that support healthy behaviour. This means that SDM with adolescents with LTCs would need to form part of healthcare policy, which is does (i.e. NICE guidelines (321)), but also be integrated systematically into healthcare delivery, which would include adequate timing for discussions, and becoming the norm in practice, which it is not (143, 270).

The Transtheoretical Model of Change has been used successfully as a theoretical framework in a number of studies with adolescents, particularly around smoking cessation and exercise (322-325), but I was unable to locate any literature around the use of Transtheoretical Model of Change in an SDM context. Despite many trials of stage-based interventions, such as the Transtheoretical Model of Change, few findings indicate that stage-based produce outcomes superior to non-stage-based interventions (326, 327). Bandura stated that human behaviour is "*too multifaceted to fit into separate, discrete stages*" and argues that "*stage thinking could constrain the scope of change-promoting interventions*"(328). The Transtheoretical Model of

Change is perhaps better suited to account for frequent behaviour, especially operationalising the issue of resisting temptation (as in smoking cessation) as well as the stages from action to maintenance. Although SDM may be viewed as a potentially habitual behaviour, with adolescents with LTCs attending several appointments annually, SDM cannot be compared to behaviours which are performed much more frequently, and integrated into habit or routine, as with smoking or physical activity. The Transtheoretical Model of Change is a model that focuses on personal motivation to intentionally change one's own behaviour. However, this neglects several critical factors for behaviour change, such as complexity of behaviour, behaviours influencing each other, and biological, social, as well as environmental influences.

3.4.5 Self-determination Theory

Self-determination Theory, developed in the early 2000s, focuses on reason or motives around behaviour regulation, and distinguishes between two types of motivation: intrinsic and extrinsic (300). Intrinsic motivation is described as the autonomous motivations relating to engaging in behaviour that fulfils personally relevant goals, which tends to make an individual feel satisfied or rewarded such as engaging in their favourite hobby or eating foods they enjoy. It is argued that such autonomous motivation satisfies the three universal, innate, and psychological needs, which are for autonomy ('*I can control my own behaviour*'), competence ('*I can master my environment*') and relatedness ('*I can develop close relationships with others*') (Figure 11). Intrinsic motivations tend to be associated with a sense of well-being and persistence of health-related behaviours. Therefore, within the context of this thesis according to Self-determination Theory, in order for adolescents with LTCs to participate in SDM they need to feel competent about being involved, feel they have control over how and to what extent they are involved, and that being involved in SDM gives them a sense of belonging. According to Self-determination Theory, an intervention should focus on what the user wants to achieve and change (intrinsic motivation) and support them in their endeavours, rather than coercing them into behaviours that they '*should*' or even '*must*' do (extrinsic motivation). The focus on intrinsic rather than extrinsic motivation could be particularly relevant in the context of research topic of this thesis, as adolescents with LTCs value being able to choose their level of involvement in discussions and decisions (230, 237, 241).

Adolescents have a strong desire to feel a sense of relatedness with others of the same age, and do not want to feel differentiated from their peers (329, 330)
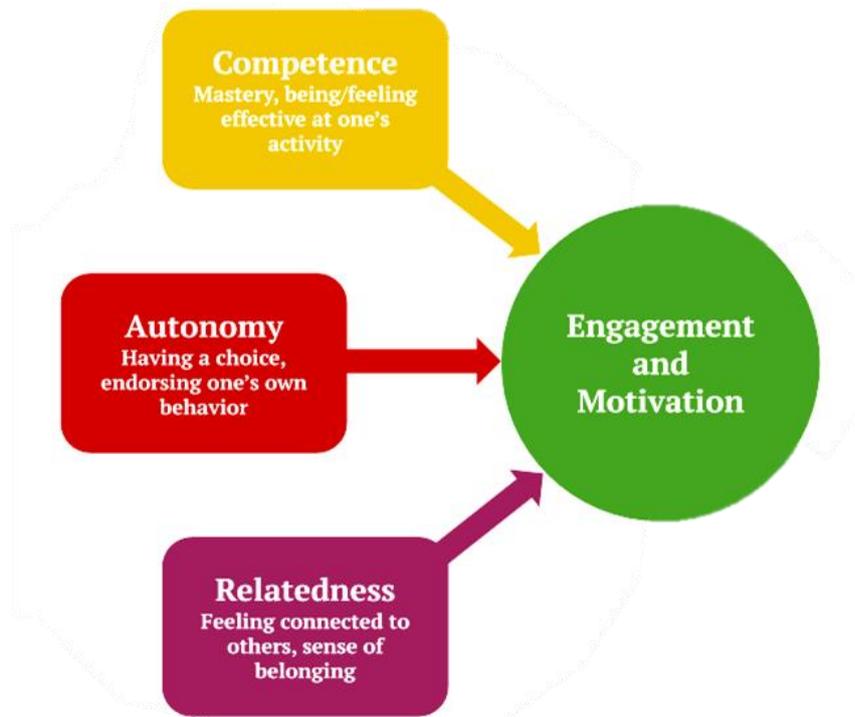
Figure 11. Self-determination theory (300)

Self-determination is a guiding principle of SDM, and was used in the development of the original SDM model for clinical practice (255). Elwyn et al (255) state that "*SDM rests on accepting that individual self-determination is a desirable goal and that clinicians need to support patients to achieve this goal, wherever feasible*". Self-determination Theory has been useful in understanding how health decisions are made (331), and decision aids have been developed using the Self-determination Theory with results including improved patient knowledge and reduced decisional conflict (332, 333). In research with adolescents, a meta-analysis including 46 studies and 15,984 participants found that autonomous forms of motivation (i.e. intrinsic motivation) had moderate, positive associations with health behaviours (334). However, evidence for Self-determination Theory is still limited compared to other established theories (e.g. the Theory of Planned Behaviour and Health Belief Model) and existing literature lacks standardisation (334). Also, Self-determination Theory identifies only three needs, whereas Maslow's widely recognised 'Hierarchy of Needs' describes a multitude of needs, which he categorized into five levels (335).

3.4.6 Information –Motivation Behavioural Skills Model

In the early 2000s, the Information-Motivation Behavioural Skills Model (299) built on the pre-existing work concerning the social and individual determinants of health behaviour, and was based on a critical review and integration of the constructs of relevant theories in social and health psychology (i.e. Theory of Planned Behaviour, Social Cognitive Theory). The Information–Motivation Behavioural Skills Model was originally developed to provide an account of the psychological determinants of human immunodeficiency virus (HIV) risk and preventive behaviour, and sought to address limitations of existing theory around these behaviours, such as the absence of specification of the relationships among critical constructs (as with the Health Belief Model and Social Cognitive Theory). The Information–Motivation Behavioural Skills Model asserts that health-related information, motivation, and behavioural skills are fundamental determinants of performance of health behaviours (Figure 12). Therefore, according to the model, the extent that adolescents with LTCs are informed about SDM and how to be involved; feel motivated to be involved; and feel they have the skills to be involved will influence their initiation and maintenance of the behaviour (SDM involvement) and experience positive health outcomes. Improving the information component of the model can involve increasing knowledge as well as challenging heuristics or misconceptions, such as fear of being labelled a 'difficult' patient if too much involvement is sought (317) or that adolescents' views are not important (204). Motivation skills are comprised of personal and social motivation, which would include adolescent attitudes around SDM, and social support of the behaviour. Behavioural skills include the objective abilities and perceived self-efficacy associated with performing the desired behaviour (SDM) such as asking questions and being involved in the discussions and decision-making processes.

The constructs within the Information–Motivation Behavioural Skills Model can be independent or interrelated. For example, being better informed about the behaviour can increase motivation and behavioural skill. However, well informed individuals may not be motivated to perform a health-related behavioural change, and highly motivated individuals may not be well informed about health promotion practices. The strength of each construct and causal pathways in influencing health behaviours depends on the target population and the given health behaviour.
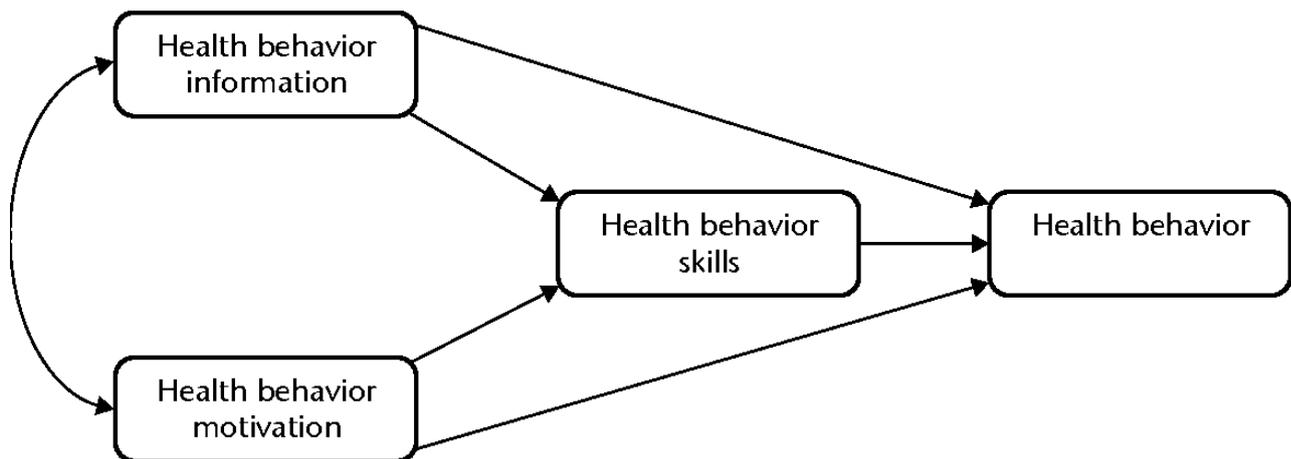
Figure 12. The Information-Motivation-Behavioural Skills Model(299)

Ten out of twelve studies retrieved in a systematic review evaluating interventions based on the Information–Motivation Behavioural Skills Model in a chronic healthcare setting reported significant positive behaviour changes, such as improved self-management (336). The Information–Motivation Behavioural Skills Model has been used to successfully predict adolescent risk as well as health promotion behaviours (337-340). However, improved motivation, knowledge and skill around a health behaviour, may not necessarily result in behaviour change (341). The Information–Motivation Behavioural Skills Model has been criticised for the lack of contextual factors, such as relationships with others and their influence on the behaviour, and the implicit assumption of this model is that individuals have complete control over their own behaviours (342). Adolescents with LTCs often feel that it is parents and HCPs who control their levels of involvement in the decision-making process (226, 227). In the context of SDM as a behavioural outcome, there is strong evidence to suggest a power imbalance in doctor-patient relationships, particularly with young patients (147), that knowledge does not equate power, and that knowledge without empowerment is insufficient (256). It is suggested that the Information–Motivation Behavioural Skills Model may be best at predicting less complex behaviour that does not tend to rely on other parties (343), as with adherence to medication regimens (336).

3.4.7 Health Action Process Approach

More recently, the Health Action Process Approach was developed in the late 2000s following a review of literature which highlighted the need to include a temporal element to the understanding of belief and behaviour (301). Health Action Process

Approach states that the health behaviour changes must be understood as a process consisting of motivation and volition phases containing action plans and action control, which is influenced by risk perception, outcome expectancies, self-efficacy, situational barriers, and support. It emphasises the importance of self-efficacy as a determinant of both intentions to action and actual behaviour.

The key component of the Health Action Process Approach is the distinction between a pre-intentional motivation stage that leads to behavioural intention and post-intentional volition processes that lead to the actual health behaviour (Figure 13). Therefore, according to the Health Action Process Approach, the adolescent would first develop an intention to be involved in SDM if they felt capable, perceive SDM as reducing risks (e.g., decisional conflict) and having a positive outcome for them (e.g., selection of the best healthcare option). Then to move to the volition process, the intention has to be transformed to detailed instruction of how to be involved in SDM (i.e., ask questions and gather information about options, consider values and preferences, discus options in line with values and preferences, and come to a collaborative decision). The adolescent would need to perceive others as supportive of the behaviour and continue feeling confidence in their ability to be involved.
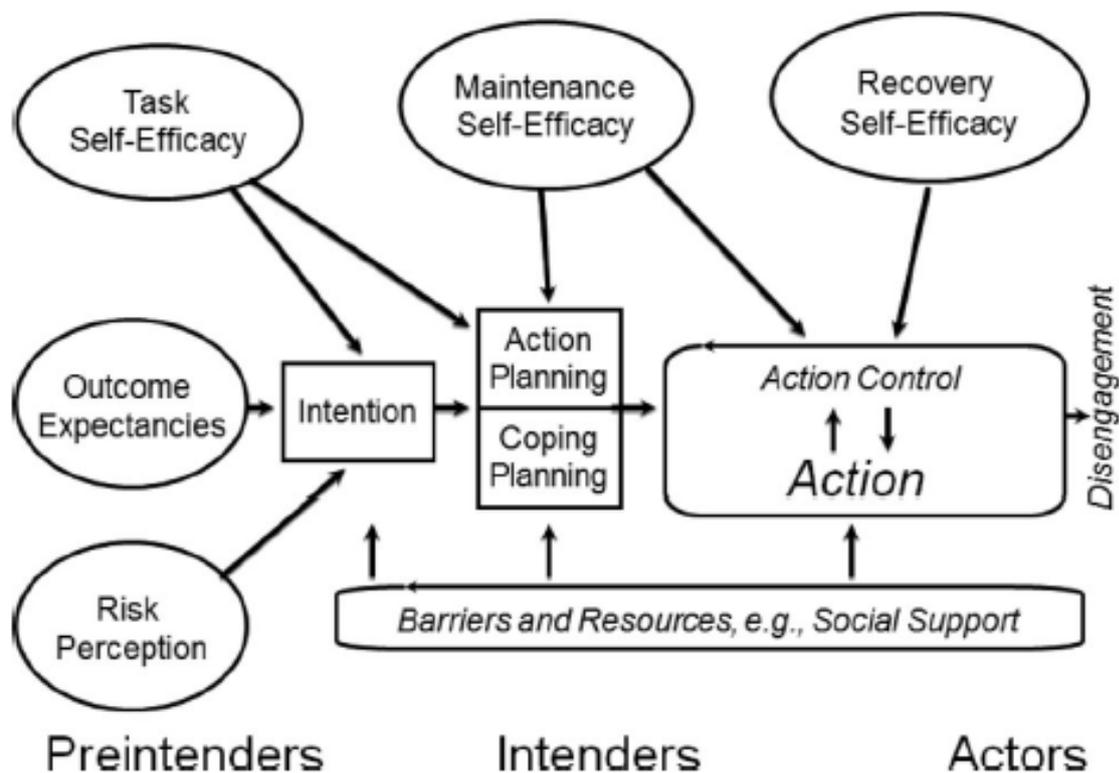
Figure 13. Health Action Process Approach (301)

A strength of the Health Action Process Approach is the inclusion of post-intentional factors to overcome the intention-behaviour gap (301). The Health Action Process Approach has been used in the development of SDM interventions (209, 344) including a pre-consultation guide for adolescents with asthma, which adolescents said increased their confidence to ask questions and their intention to do so in future consultations (209). However, a meta-analysis of studies applying the Health Action Process Approach in health behaviour contexts found that self-efficacy (action and maintenance related) was the only component of the model that had an effect on behaviour, which was a small to medium effect size (345). As with other models, such as the Health Belief Model (294), the Health Action Process Approach fails to adequately consider the roles of social and environmental factors surrounding behaviour and behaviour change, and views individuals as conscious processors of information.

3.4.8 The need for more than theory alone

With an abundance of existing theories for behaviour change available, researchers often pick certain theories, but do not offer any explanation why these were selected (289). Authors sometimes select whichever theories have received the most attention at the time (346). Frequency of theory use does not necessarily reflect the quality of the theory in relation to its ability to explain behaviour or behaviour change (289). Many of the aforementioned theories contain overlapping concepts, particularly in regards to self-efficacy and perceived behavioural outcomes, and frameworks have been created in attempts to integrate pre-existing theories (e.g. Theoretical Domains Framework, discussed below (202)). The theoretical models for behaviour and behaviour change, as described above, can provide insight into how to understand and modify behaviour and can be used to inform intervention development. However, they do not provide clear guidance on the development process of interventions aimed at achieving the desired behavioural outcome or outcomes. In recent years, a number of journal articles, websites and books have been published detailing how to develop interventions so that others could follow, including the Person Based Approach and MRC guidance (167, 200, 347). In line with the O'Cathain and colleagues taxonomy of health intervention methods (347), I will use the term 'approaches' in this thesis to refer to what could be described as

guides, guidance, methodology or frameworks proposing ways of developing health interventions.

3.5 Approaches to developing interventions for health improvement

A taxonomy of health intervention methods based on a systematic review identified eight categories of approaches which include: partnership, target population centred, theory and evidence-based, implementation-based, efficiency based, stepped or phased based, intervention-specific, and combination (347). This PhD thesis aims to integrate evidence and theory into the proposed intervention, with the users at the forefront of its development. The person-based approach (200) is defined as target population-centred, and the MRC guidance advocates a theory and evidence-based approach (347). The following theory and evidence-based approaches will be also discussed; Theoretical Domains Framework (TDF) (202), Behaviour Change Wheel (348) the Intervention Mapping Approach (IMA).

3.5.1 Theoretical Domains Framework

With lack of guidance of how to select appropriate behaviour change techniques, one approach to addressing the vast number of existing, often overlapping theories is the Theoretical Domains Framework (TDF) (202). The TDF was developed in 2012 by psychologists and implementation researchers, informed by 128 explanatory constructs from 33 behaviour change techniques in order to explain barriers and facilitators of behaviour in any given situation. The TDF has been used in a variety of contexts to understand behaviour and design interventions. The TDF domains have been used previously to explore clinicians' perceptions of barriers and facilitators to SDM in youth mental health (271), and across many other contexts involving young people including to: understand behaviours (e.g. sexual health service use, physical activity, and screen use), inform theoretically developed interventions, and to identify problems in guideline implementation (349-352).

A key strength of the TDF is the comprehensive coverage of the possible influences on behaviour by including 14 domains, and clarity about each of the domains, as each is specified by component constructs from 33 theories of behaviour (Table 9). Findings from the validation study by Cane and colleagues (202) have strengthened the evidence for both the structure and content of the domains. This has also

increased confidence in the usefulness of the TDF and its application in different contexts, laying the foundations for theoretically informed interventions.

Table 9. Domains of the Theoretical Domains Framework (202)

1) Knowledge
2) Skills
3) Social/Professional Role and Identity
4) Beliefs about capabilities
5) Optimism
6) Beliefs about consequences
7) Reinforcement
8) Intentions
9) Goals
10) Memory, Attention and Decision processes
11) Environmental Context and Resources
12) Social Influences
13) Emotions
14) Behavioural Regulation

The limitations of the TDF when used alone highlight the need to advance understandings regarding the development, implementation, and evaluation of behaviour change interventions. As part of this, it is important to find ways to understand the content of the intervention and be able to establish the 'active ingredients' for change. This highlights the need to utilise a method for classifying the content of interventions alongside the TDF as an approach, as the TDF provides no detail about to how to undertake action (347). The TDF is very often integrated into, and used with, the Behaviour Change Wheel (348).

3.5.2 Behaviour Change Wheel

At around the same time as the TDF, Michie and colleagues developed the Behaviour Change Wheel (348) in response to the need for a more comprehensive theory-based framework for intervention development, which can be applied to a variety of contexts. The development of the Behaviour Change Wheel was the result of a systematic literature review which identified and synthesised 19 frameworks of behaviour change. The Behaviour Change Wheel is comprised of three layers, the COM-B model (Capability, Opportunity, and Motivation to Behaviour) forms the central part of the wheel of behaviour that an intervention could target based on its included components. Nine intervention functions (e.g., training, education, persuasion) surround the central COM-B and the outer layer includes seven policy

categories that support the delivery of the intervention functions (e.g., legislation, service provision, guidelines) (Figure 14). The Behaviour Change Wheel has been used in the development of a number of interventions aimed at changing health behaviour in adolescent populations (349, 353), including a mobile application which aimed to improve LTC management (354). It has also been used in the development of SDM interventions (355, 356), including a booklet aiming to prepare patients to participate in SDM (357), which showed evidence of effectively addressing SDM barriers.
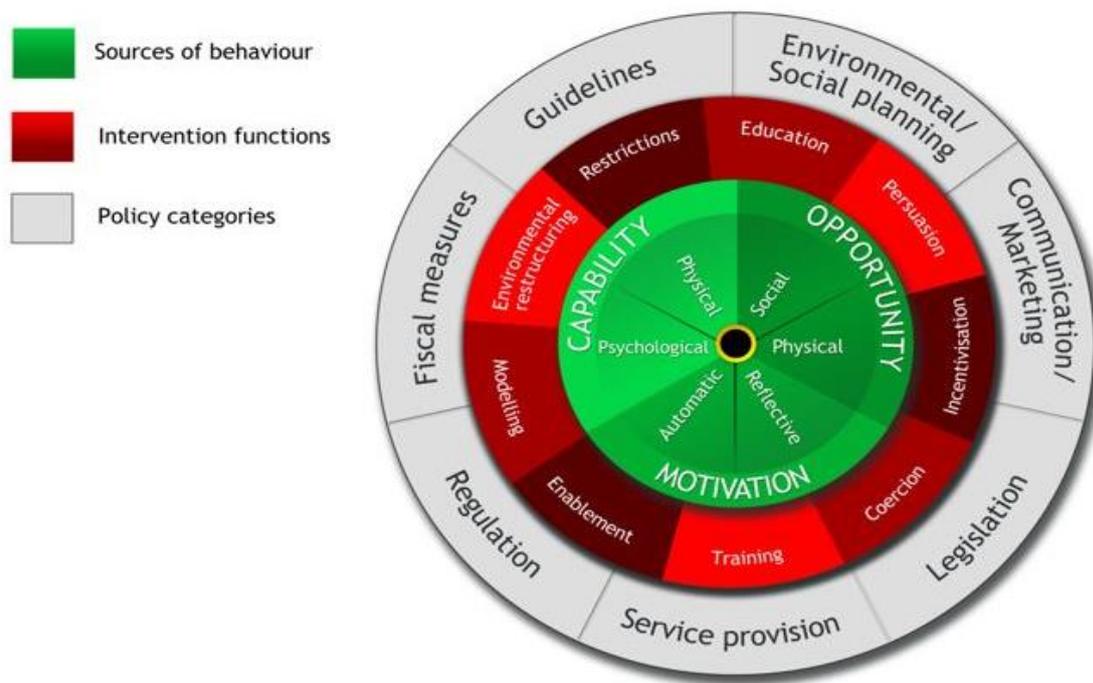
Figure 14. The Behaviour Change Wheel (348)

The COM-B model is used to perform a 'behavioural analysis' of the target behaviour, which involves gaining an understanding of the barriers and facilitators around the target behaviour (i.e., SDM involvement). Mapping the barriers and facilitators onto the COM-B model is the first stage of the wheel, called sources of behaviour. The arrows in the COM-B model represent potential for causal inference (Figure 15). This 'behaviour system' is at the centre of the Behaviour Change Wheel and involves three essential conditions which influence behaviour: Capability, Opportunity, and Motivation. Capability accounts for the individual's physical and psychological ability to engage in the behaviour. Therefore, like self-efficacy, relating to SDM, adolescents would need to have confidence in their psychological and physical ability to be involved in discussions and decisions about their healthcare

options. Opportunity is defined as external factors outside of the individual that prompt or make the behaviour possible. Similar to social norms, according to the COM-B model adolescents would need to feel that others (e.g., parents, HCPs, and peers) both allow and encourage their involvement in SDM, and that the environment, for example clinic location and appointment timing, enables the behaviour. Motivation includes goals, and conscious decision-making, as well as the brain processes that energise and direct behaviour, including habit processes and emotional response. Both capability and opportunity can influence motivation.
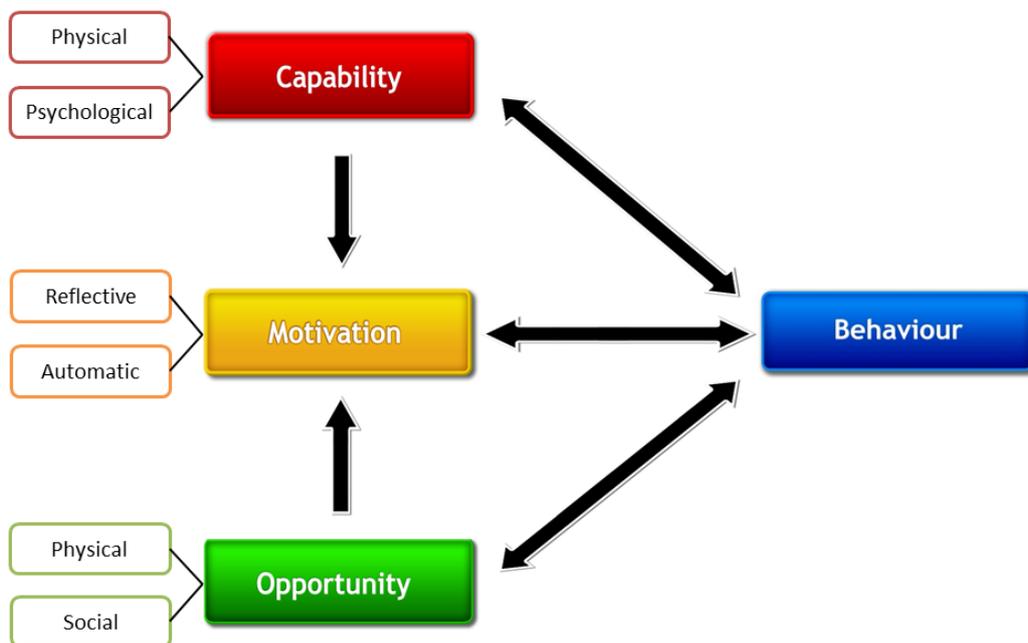
Figure 15. COM-B model (348)

Targeting motivation according to the COM-B model could involve increasing awareness about the benefits of SDM, attempting to elicit positive emotions around involvement, and habit-forming behaviour around SDM (e.g., automatically asking questions and engaging in discussions with HCPs around healthcare options). To sum up, according to the COM-B model, in order for adolescents to engage in SDM, the process is to be understood from these angles and address the following questions: '*do adolescents feel as though they are able to be involved?*' '*are they allowed, or encouraged to be involved?*' and '*are they motivated to be involved?*' Using this model, an intervention would aim to prepare adolescents with LTCs so that they feel they have adequate ability to be involved in SDM, encourage, and let them know that it is their right, as well as drawing attention to motivating factors which promote involvement, such as SDM benefits. Using the COB-B model in

intervention development can provide a systematic and standardised approach, and allows for theoretically based behaviour change techniques to be applied as a guide for behaviour change.

The sources of behaviour identified by mapping barriers and facilitators to the COM-B model constructs then determine which intervention functions (the type of intervention) which will determine the behaviour change techniques (intervention content). Finally, suggested policy categories and mode of intervention delivery are considered to guide the researcher on how the intervention could be implemented to bring about the behaviour change.

When I explored the possibility utilising the of the Behaviour Change Wheel to develop the intervention for this PhD thesis, the amount of choice for selecting intervention functions and policy categories was overwhelming because the nature of the proposed intervention meant that all possibilities were available. This can lead to a tendency to want to include everything, rather than creating a targeted intervention. The Behaviour Change Wheel has also been criticised for being overly formulaic and rigid in its attempt to limit variability, which is ineffective in a discipline with ample variation (285). Michie et al. (358) recognised the Intervention Mapping Approach (IMA) (201) as a useful, alternative framework which has contributed to making intervention design more systematic.

3.5.3 Intervention Mapping Approach

The Intervention Mapping Approach (IMA) was originally developed and introduced in 1998 by Bartholomew and colleagues as a systematic planning framework for designing theory and evidence-based health promotion programmes, including materials that aim to address programme outcomes and objectives to match specific populations and contexts (290). The IMA maps the path of intervention development from the problem towards the solution, working through six stages (Figure 16). Each stage includes a number of tasks, where completion is required to create foundations for the following stage. The stages in the context of developing an intervention aimed to improve SDM with adolescents in long-term healthcare will be discussed more in depth in Chapter 5.

The six steps and related tasks of the IMA process involve firstly conducting a needs assessment or problem analysis, identifying what, if anything, needs to be changed

and for whom. The second step is to create a matrix of change objectives by combining behaviours (performance objectives) with behavioural determinants (what can cause or prevent the behaviours) and identifying which beliefs should be targeted by the intervention. The third step is to select the theory-based intervention methods that match the determinants into which the identified beliefs aggregate. The determinants can then be translated into practical applications which meet the parameters for effectiveness of the selected methods. The fourth step of IMA involves integrating methods and the practical applications into an organized intervention programme. The fifth step includes planning for adoption, implementation, and sustainability of the programme in real-life contexts. Then the final step of IMA involves generating an evaluation plan to conduct effect and process evaluations.
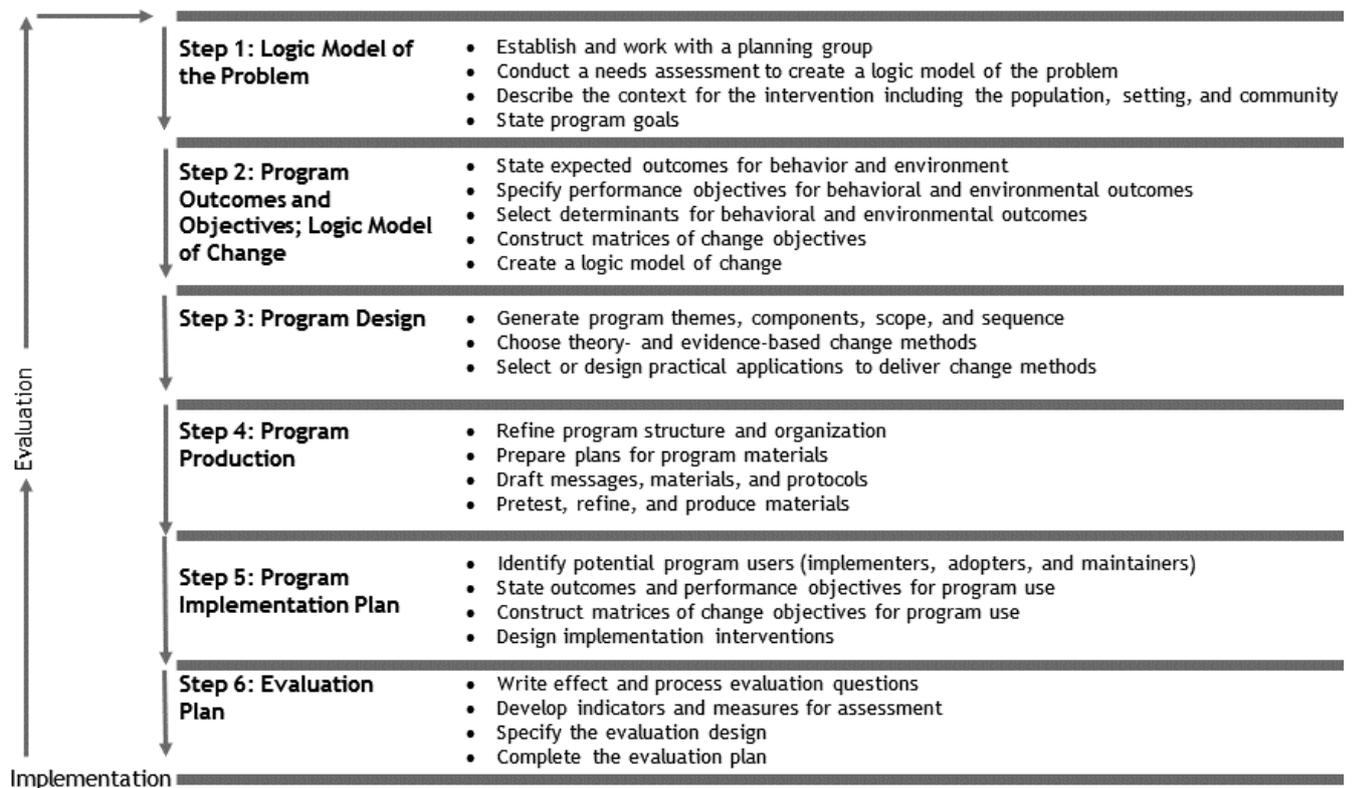
Figure 16. Six stages of the Intervention mapping Approach (201)

The IMA is a protocol for systematic theory and evidenced-based planning for behaviour change (201), which fulfils criteria recommended in the MRC framework and provides a logical process for effective decision-making, including how to integrate theory and evidence throughout intervention development. The IMA is based on a multi-theory and evidence-based approach, and highlights the

importance of stakeholder input throughout the intervention development process. A strong point of the IMA is it first involves mapping out the problem, instead of starting with theory, which can lead to ignoring important factors that do not fit into a single existing theory, or could hinder one from addressing known problems in a new way (359). The IMA therefore ensures the intervention development is guided by the problem, as opposed to dismissing important factors by prematurely selecting theory.

3.5.4 Approaches to developing an intervention to prepare and support adolescents with long-term conditions to be involved in shared decision-making

The Person Based Approach provides a philosophical basis for the development of the intervention described in this PhD thesis due to its user-centredness, as mentioned above. The paper published by Yardley and colleagues (200) describes the Person Based Approach, providing guidelines to intervention development with examples. However, there are no comprehensive, step-by-step instructions to the Person Based approach, such as included in the Barholomew et al's 650-page book on the IMA published in 2016 (201). The IMA is not restricted to one particular theory, advocating the use of multiple theories alongside evidence for describing and addressing the factors to achieve change (201). Due to the abundance of pre-existing, and potentially relevant theories, and a lack of pre-existing guidance or literature around the topic of SDM interventions for with adolescents with LTCs, the IMA seemed to be the most appropriate approach and the most in line with Yardley's (200) Person Based Approach, where users come first and theory second. Therefore, due to the flexible yet systematic attributes of the IMA, I decided it would be the best suited approach to be used alongside the Person Based Approach and MRC framework working from a problem-driven perspective where relevant theory is selected as a result of the information gathering from users (201).

Peters and Crutzjen (286) argue for pragmatic nihilism which drops the assumption that psychological barriers need to exist as units. Pragmatic nihilism stresses that researchers should not conduct interventions based upon one theory, rather they should research the target population's psychology. This would move from theoretical perspective to a more flexible integration of theories. They also argue for pragmatic nihilism as a complementary, useful perspective rather than an alternative concept (286). This provides further support for using the IMA to develop the

intervention aiming to prepare and support adolescents with LTCs to be involved in SDM.

The research included in this PhD will only cover steps 1 to 4 of the IMA which will be discussed in detail in Chapter 5. A protocol for steps 5 (programme implementation) and 6 (programme evaluation) will then be proposed in Chapter 7.

3.6 Discussion

This chapter describes and critically appraises several theories and models which can be used as tools in the intervention development process. By developing an understanding of how the models work within the context of SDM with adolescents with LTCs, each model can be considered when deciding on intervention components. Overlap between the existing models is apparent, and each of the models, theories and approaches discussed in this chapter have strengths and weaknesses within the context of SDM with adolescents with LTCs. Overall, nearly all the described models of behaviour and behaviour change suggest the importance of self-efficacy in relation to SDM, and the importance that adolescents with LTCs feel they have adequate skills to be involved. The concept of attitudes around, and evaluation of, the target behaviour means that adolescents with LTCs need to be aware of, and value SDM outcomes for themselves. It is suggested that social influence has a substantial impact on behaviour, that adolescents with LTCs need to feel that others support and encourage their involvement in SDM, and that it is a normal thing to do. However, by selecting only one theory to facilitate intervention development, there exists the potential for gaps within the model leading to important factors being overlooked. One example discussed is emotion, which is a commonly absent from the theoretical models, and potentially important for my target population. Evidence has shown that although theory-driven interventions may improve theoretical constructs (e.g., self-efficacy, knowledge), or intention to perform the target behaviour, it may not actually lead to behaviour change (314, 341). This PhD thesis takes a problem-driven perspective using the Person Based Approach following the comprehensive steps of the IMA in attempt to ensure maximum intervention success, which involves a systematic approach to intervention development, and can incorporate the use of multiple theories as opposed to one alone.

The IMA was adopted for the research presented in this thesis as its systematic nature ensures that the development and content of the intervention is clear, and it guides the appropriate selection of theory for establishing the causal mechanisms underpinning the intervention to maximise its effectiveness. The importance of theory throughout the IMA process will become evident in Chapter 5, where the first 4 stages are outlined with examples of how they will be applied to SDM with adolescents with LTCs. The aims of this PhD are to investigate how to improve SDM with adolescents with LTCs in order to develop a theory and evidence-based intervention. By integrating the Person Based Approach and IMA, I will begin by trying to understand the problem from the user perspective. The first step of the IMA involves exploring adolescents' preferences and experiences around involvement in decision-making about their healthcare, and what they perceive to be barriers and facilitators to SDM. The description of this process in the previous chapter, and will continue in Chapter 4, aiming to fill the identified gaps, providing a clearer focus on the specified population and behaviour of interest. Using the Person Based Approach, the person (adolescents with LTCs) will be at the forefront of the research, the data will be interpreted inductively, and a set of guiding principles for the intervention will be developed in the form of logic models created following the step-by-step IMA. However, where these data fit with theories that I have identified, relevant constructs can be used to help organise data using the IMA and assist and suggest intervention points and methods. Consideration of theoretical models during intervention development, alongside existing literature and qualitative interviews with adolescents could lead to the development of an intervention that has the potential to improve their involvement in SDM, thus hopefully improving patient care, satisfaction with care as well as satisfaction with decisions made about their healthcare.

3.6.1 Conclusions

This chapter discusses theoretical constructs in relation to the participation of adolescents with LTCs in SDM, as well as approaches to intervention development. The following chapter will aim to further investigate this phenomenon of interest in order to attempt to select the most appropriate theory and inform the development of an intervention aiming to prepare and support the involvement of adolescents with LTCs in SDM.

Chapter 4: "I'd like to have more of a say because it's my body": Adolescents' perceptions around barriers to, and facilitators for shared decision-making

4.1 Chapter overview

This chapter reports findings from a qualitative interview study with 19 adolescents with long-term conditions (LTCs) using participatory methods. A version of the chapter has been published as an article with the same title in the '*Journal of Adolescent Health*' in July 2019 (279) (appendix 2). The chapter contributes to thesis Objective 3 and is instrumental to informing the intervention development by enabling the exploration of barriers to, and facilitators for shared decision-making (SDM) as perceived by the target audience. This chapter also adds insight into what adolescents deem to be useful and acceptable in terms of intervention delivery, design, and content. Implications for an SDM intervention targeted at adolescents with LTCs are discussed.

4.2 Introduction

At the Intervention Planning Stage of the Person Based Approach (200), drawing on previous evidence (Chapter 2), theory (Chapter 3) and the perspectives of the people who will use the intervention (this Chapter) are each deemed equally important and complementary. Qualitative research should be carried out to elicit users' views of the planned behaviour changes, including relevant previous experience and barriers and facilitators (200). Through qualitative methods, the wider individual and social influences on health behaviour can be explored which, as described in the preceding chapters, are likely to influence the involvement of adolescents with LTCs in SDM. One of the main findings discussed in Chapter 2 is the discrepancy between adolescents' preferences for decision-making involvement and their actual experiences. Therefore, perceptions around these discrepancies are further explored in this chapter and contribute to the understanding of perceived barriers and facilitators around SDM involvement.

As reported in Chapter 2, adolescents with LTCs often feel as though they are left out of discussions and decisions with Healthcare Professionals (HCPs), which can give them the impression that their views are not important (204). SDM does not occur consistently in clinical encounters, and adolescents with LTCs often act as

bystanders (101, 102). Furthermore, previous literature examining these encounters often focuses on parents' and HCPs' experiences, often omitting the young person's narrative (143, 204). To date, no study has specifically focused on the narratives of adolescents with LTCs around the perceived barriers to, and facilitators for their involvement in SDM. Narratives are generally understood as stories that order events across time, and structure accounts of these events in ways that give meaning to the experience of storytellers (360).

4.2.1 Chapter aims and objectives

The aim of this qualitative study was to explore the narratives of adolescents with long-term conditions, including their perspectives and experiences around SDM. The objectives were to (a) understand adolescents' experiences and preferences around the roles of individuals involved in the decision-making process, including reasons for discrepancies between the preferences and experiences; (b) identify barriers to, and facilitators for, adolescents' involvement in SDM from their perspective; (c) gain insight into what would be an acceptable for an intervention for SDM participation, in terms of format, delivery, design and content. These findings will be used to inform the development of an intervention aimed at supporting SDM with this population (Chapter 5).

4.3 Methods

4.3.1 Participants and recruitment

4.3.1.1 Inclusion Criteria

Given the study's focus on adolescent involvement during clinical encounters, I decided that eligible participants had to have been living with a long-term condition for at least a year. The participant age range was stipulated as 12 to 19 years. This was because although the World Health Organization (WHO) defines adolescence as 10 to 19 years, the systematic review discussed in Chapter 2 identified a difference in involvement preferences between younger (aged 11 and under) and older adolescents (aged 12 to 19) (204). Adolescents under 12 years are likely to require more support from parents with both the decision-making process and the responsibility for condition management (28-32, 229)

Other qualitative studies which explored adolescents' attitudes and experiences towards health services (236, 361) found saturation to be reached with 20

participants, therefore this was the original aim for participant recruitment. Eligible participants were identified by HCPs from both young adult (transitional) and paediatric neurology, endocrinology, nephrology clinics, and the paediatric rheumatology clinic at regional secondary care clinics. There is currently no transitional rheumatology clinic at this site. The four clinical areas were selected as patients attending these clinics tend to have long-term conditions which have distinct characteristics from one another in order to explore a range of experiences with the condition, self-management options, and healthcare decision-making. For example, diabetes can be complicated to self-manage, but if managed well participants can lead a relatively normal life. Epilepsy, which is generally only managed with medication, is characterised by unpredictability, and apart from seizures is usually invisible. Kidney conditions vary in severity, generally worsen over time and can be visible due to scars or catheter use. Arthritic conditions, which can also be visible, are characterised by periods of remission and flares, people living with arthritis can at times be suffering constant pain.

All the aforementioned conditions often persist into adulthood, affect the patients' lives substantially, and have a range of management options, allowing for the ideal environment for SDM. Due to the number of studies looking at healthcare decision-making involvement with adolescents with cancer in the systematic review outlined in Chapter 2 (10 out of 27 included in the thematic synthesis and 4 studies identified later), I decided not to recruit from oncology clinics so that views from adolescents with a breadth of conditions could be represented to inform the intervention development.

A purposive sample was attempted to include an equal number of male/female participants from each clinic (condition), and those aged between 12-15 and 16-19 to allow for a broad representation of adolescents. Potential participants were purposefully identified by members of their clinical team and approached in attempt to obtain an even distribution of ages, genders and LTCs. Demographic data of participants including gender, age and LTC of all approached participants were noted. Further demographic data were collected from the respondents including ethnic identity and elapsed time since diagnosis.

4.3.1.2 Recruitment

Once an eligible participant had been identified, participants and parents were asked for permission to be approached by the researcher (myself). When conducting qualitative research with adolescents, it has been suggested that it is useful for the interviewer to have contact with the participant before the interview in order to be viewed as approachable, which can improve trust and recruitment in a hard to reach population (362). If permission to be approached had been given, I introduced myself and the study to parents and potential participants, and provided them with packs including information sheets, a consent-to-contact form, and a stamped self-addressed envelope for the form to be returned (Appendix 3). Participants and parents were also given the opportunity to ask questions at this point. All study materials for adolescents including participant information sheets, consent and assent forms were piloted with two adolescents who were known to me personally, to ensure comprehension and acceptability in this age group.

Participants were able to choose the interview site, which allows them to identify a space where they feel most comfortable (362). If interested participants were under 16 years, interviews were arranged via the parents. Interviews took place either at hospital sites in an empty room, the participants' homes, or a quiet public location (e.g., café or food court) at a table away from any other customers or employees. Allowing participants to select an environment where they feel safe and comfortable can assist with developing rapport (363). Participants provided informed consent, and for those under 16 years, parental consent was obtained as well as participant assent.

4.3.2 Participatory interviews

The findings in Chapter 2 identified that adolescent preferences and experiences can vary substantially between individuals. Therefore, individual interviews were selected as the data collection method. This also enabled comparison across age, gender, and health condition. Semi-structured interviews were initially piloted informally with two males who were known to me personally, aged 15 and 16. Although neither had been diagnosed with an LTC, they had recent experiences of doctors' visits involving decision-making, and they were able to provide their impressions on the comprehension, appropriateness and acceptability of the interview questions and overall process for people of a similar age group. As the adolescents were known to

me previously, they may have felt more at ease voicing an open and critical evaluation of the interview process. Feedback after piloting the initial interview questions included finding the process "boring" and overly formal. Other ideas for interview techniques were tested afterwards with more success and were therefore selected for the interview process. These included life grids (364) and pie charts (239).

These participatory interviews were conducted to explore the adolescents' narratives and identify possible barriers and facilitators to SDM. All interviews were audio-recorded with signed consent, and transcribed verbatim. Participants were given the opportunity to review and amend transcripts to ensure they reflected participants' views. Interviews consisted of three parts; life grids (364), pie charts (239) and semi-structured questions, which are described below.

4.3.2.1 Interview Part 1: Life Grids

After the appropriate signed consent had been obtained, the interviews began with an informal chat in attempt to build rapport prior to initiating the recording device. I introduced myself, explained where I was from and what I was studying, then proceeded to ask participants how they were, how their day/weekend/half term was going, and what they had done, depending on the context. The beginning of a qualitative interview can be met with initial apprehension from the interviewee, characterised by uncertainty, where the first questions should be broad, open-ended and non-threatening (363). This allows the researcher to begin developing rapport with the participant (363). Building rapport with this participant population (adolescents with LTCs) may be particularly important due to the potential for perceived power imbalance between participant and researcher, who is seen as being in control of the interview process, as adolescents with LTCs are critical of the power imbalance they often experience with the adults during healthcare consultations (204).

I then explained the process of the interviews, emphasising that the participants could choose whether or not to participate in the various parts. Participants were first asked to complete a life grid (364) with important life events surrounding their health and health condition including doctors' visits. At the top of the grid are columns for year, age, school, doctors' visits, and empty columns for which participants could

add headings of their choosing. The suggested headings were included at the top of the grid to help participants get started, and encourage participants to speak about consultations with HCPs (e.g., "doctor's visit") (Figure 17). I explained that they did not have to complete all columns, but could cross reference the year with their age, school year and anything that was going on with their condition at the time, as an example. Once I had described the activity to the participants, I provided a brief demonstration and asked if they understood. Some participants checked to if they were completing the grids correctly by asking questions like "*Is this okay?*" or "*Should I put this here?*" to which I reiterated that they could complete the grids however they liked. Participants were given as much time as they wanted to complete this activity. Some completed the grid in silence then described it afterwards, and others narrated while they wrote on the grids. If participants appeared to be struggling to start the task, I suggested beginning by putting dates in the left-hand column starting with the year they were born. This seemed to help initiate the process as they then completed the other columns with additional information. One participant (Bethan), who stated that she could not write, asked me to fill in the grid for her while she provided instructions. I prompted participants to expand on certain events by asking: "*could you tell me more about that*?".

The life grid, as defined by Wilson et al. (364), was found to be instrumental in 'breaking the ice' at the beginning of the interview with vulnerable young people. This occurred due to the positioning of the interviewer and respondent which was informal, averting the need to sustain eye contact and possibly countered the respondent's perception of the interviewer as an authority figure. It also afforded the respondents a degree of control over disclosure of sensitive issues. The completion of the grid becomes a 'mutual collaboration' where the researcher relinquishes some control over data collection enabling the respondent to assert influence over their own narratives, reflecting on their interpretation on past events. Parry et al (365) found that this process of collaboration enabled respondents to reflect upon their interpretations of past events, and eased the discussion of sensitive issues. This collaborative encounter mirrors the desired interactions which might take place during SDM. Participants were invited to discuss what they wanted using the life grids but were asked specifically to describe events around clinical encounters and prompted with questions, such as "*could you describe this doctors' visit to me?*", "*can*

you remember what was discussed at this doctor's visit"?, and *"What decisions were made at this time?".*

4.3.2.2 Interview Part 2: Pie Charts

Where participants indicated doctors' visits on the life grids, I asked about any healthcare decisions that may have taken place. For example, all participants indicated on the life grids when they were diagnosed with their LTC. Although some were too young to remember at the time, many were able to iterate the initial decision to begin treatment, for example. Where any healthcare decision could be remembered, I asked the participant to consider the specific decision which was made and to complete pie charts (239) indicating both the experienced and preferred roles of those involved in the decisions (Figure 18). Experienced roles in the pie charts were described as "*real*" and preferred roles described as "*ideal*". Possible reasons for discrepancies between the '*real*' and '*ideal*' roles, and potential enablers of involvement were then explored by asking questions around the preferred and experienced roles using the pie charts as reference. Such questions included "*Why do you think the decision was like this (real roles) and not like this (ideal roles)?*", "*Why do you think it is important for the decision to be like this (ideal roles)?*" and "*What could have helped the decision to be more like this (ideal roles)"?*

These pie charts had been successfully used by Lipstein et al (239) in a study which explored adolescents' roles and preferences in treatment decisions for long-term illness. However, Lipstein and colleagues did not focus on potential explanations for the mismatch between the desired and experienced roles (239).

4.3.2.3 Interview Part 3: Semi-structured follow up questions

A follow-up semi-structured interview schedule was derived from the findings of Chapter 2 (Table 10) to address gaps in the systematic review including exploring what respondents feel should be the roles of those involved in the clinical encounters, as well as what may motivate or inhibit their participation in SDM. The last stage of the interviews also included questions about potential intervention ideas. When piloting the interview schedule, the two adolescents found difficulty with the word '*intervention*', which is associated with attempting to overcome addiction. The adolescents felt that '*health materials'* would be the most appropriate term. In

the interviews, participants were asked about previous experiences with health information materials, and suggestions about what to include or avoid were elicited.

If questions on the interview schedule had already been addressed in the preceding parts of the interview, questions were not asked again to avoid repetition and attempt to emulate a more informal chat, as opposed to being strictly regimented to following the specific questions and question order. I looked for cues as to whether or not the participants were happy to continue or understood the question, such as facial expressions. If it appeared that they had not understood, I rephrased the question to clarify. Although I did not notice any discomfort expressed by participants, had it been the case, I had planned to ask if they wanted to skip the question or stop the interview. A flexible approach to interviewing, responsive to the individual participants' needs, can help to maintain rapport between the interviewer and participant (363).

Participants' Life Grids	Examples of adolescents' experiences around decisions during clinical encounters
<table><tr><th>Year</th><th>Age</th><th>School</th><th>Doctor's Visits</th><th></th><th></th></tr><tr><td>2013</td><td>11</td><td>comprehensive School</td><td>more seizures Lamotrigine</td><td>diagnosed nocturnal epilepsy</td><td></td></tr><tr><td></td><td></td><td>GCSEs</td><td></td><td></td><td></td></tr><tr><td>2018</td><td>16</td><td></td><td>Keppra ↓ Oxford</td><td>myoclonic seizures</td><td></td></tr></table>	"*I've been on three different medications, so first they put me on the first one which was Lamotrigine, I'm still on that now, and then earlier this year, in March I think, they put me on a new one, called Keppra, and they were gonna do like so I'd have both of them, but then turn it into a crossover, so then I'd change onto it, but that had bad side-effects, and I wasn't happy with it, so I think last month I was put on a new one again*" (Lisa, aged 16, neurology, 5 years)
<table><tr><td>2009</td><td></td><td></td><td></td><td></td></tr><tr><td>2010</td><td></td><td>High School</td><td></td><td></td></tr><tr><td>2011</td><td></td><td></td><td></td><td></td></tr><tr><td>2012</td><td></td><td></td><td></td><td></td></tr><tr><td>2013</td><td></td><td>SATS</td><td></td><td></td></tr><tr><td>2014</td><td></td><td></td><td></td><td></td></tr><tr><td>2015</td><td></td><td>GCSE's</td><td>Diagnosed with diabetes.</td><td></td></tr><tr><td>2016</td><td></td><td></td><td></td><td></td></tr><tr><td>2017</td><td></td><td></td><td></td><td></td></tr><tr><td>2018</td><td></td><td></td><td>5 injections</td><td></td></tr></table>	"*I think last year, around summertime when the exam season started, um as I said before I used to do three times [insulin injections] a day, but then um the doctor suggested to me, so I can give a bit higher insulin in the morning, so it goes around to lunchtime, and then when I get home I can control it because when you have exams the diabetes is like a little fabric ball that you push away to the side*" (Adam, aged 13, endocrinology, 13 years)
<table><tr><td>07</td><td>7/8.</td><td></td><td>Opthamologist /audiology.</td><td></td></tr><tr><td>08</td><td></td><td></td><td></td><td></td></tr><tr><td>09</td><td></td><td></td><td></td><td></td></tr><tr><td>10</td><td></td><td></td><td></td><td></td></tr><tr><td>11</td><td></td><td></td><td></td><td></td></tr><tr><td>12</td><td></td><td></td><td></td><td></td></tr><tr><td>13</td><td></td><td></td><td></td><td></td></tr><tr><td>14</td><td></td><td></td><td></td><td></td></tr><tr><td>15</td><td>15/16.</td><td></td><td>Renal /surgery.</td><td></td></tr><tr><td>16</td><td></td><td></td><td></td><td></td></tr></table>	"*they would explain it [surgery] as well at every appointment, so they would keep bringing it up, seeing if I wanted it again just to check I hadn't changed my mind. And obviously at the time I was under 18, so it's not as if it would have been solely my decision anyway, it would have been my parents, but my parents felt they should pass it on to me. I must have been about 12 at the last appointment. And then ever since then I've stopped seeing 'em because I don't want to have it done.*" (Laura, aged 18, nephrology, 5 years)

Figure 17. Life Grids depicting adolescents' lived experiences around their long-term conditions

Adolescents' perception of roles in a healthcare decision	Adolescents' desired roles in a healthcare decision	Adolescents' explanation of "real" versus "ideal" roles
		"I guess cuz like the neurologist said I should, my parents said to give it another go, and my epilepsy was so bad I had to give it a try again, even if I didn't want to I had to try." (Caitlin, aged 18, neurology, 15 years)
		"Maybe equal, maybe not my parents so much. I'm old enough now, like yeah, they don't need a say, they did before but that should change. I should have a say, and understand why and what I'm taking, you know?" (Adam, aged 13, endocrinology, 13 years)
		"Not everything the doctor says is clear like for us to understand so you know, having a say or asking questions may, like, make us understand more. So, I can know what I have to do or if I was confused about something that, we should have our own say." (Gareth, aged 19, nephrology, 10 years)
		"Because obviously I was just diagnosed, and they were like: "if you want to try it, you can try it, and then if you don't like it, you don't have to go on with it". I tried it for about maybe two weeks." (Lydia, aged 15, endocrinology, 5 years)
		"I would have made the decision myself anyway cuz I knew at the time I wanted to go off it, that's what I had in my head. Um I guess I could have let them have a little say in it but it's just what I wanted to do so I, I would have allowed them like a quarter, not even that, because I at the time, I was determined I didn't want to be on any medication, so yeah" (Bethan, aged 18, nephrology, 18 years)
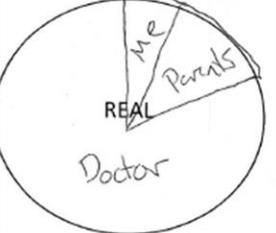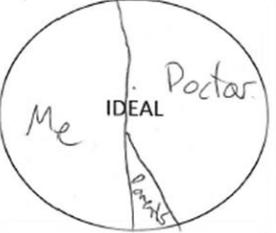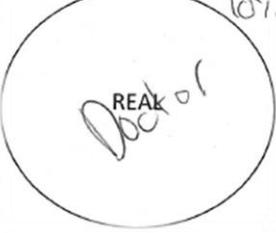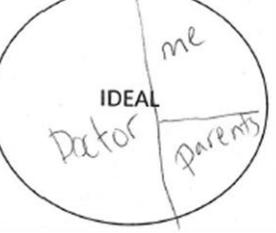
Figure 18. Pie charts allocating perceived and desired roles in healthcare decision-making

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Table 10. Semi-structured interview schedule

	Sample Interview Questions	Sample Follow up Questions
	Participant perspectives around SDM	
1.	How have treatment options been presented to you in the past?	*How do you think treatment options should be presented?*
2.	What do you think your/your parents'/HCPs' roles should be in decisions and discussions?	*How does this compare to your actual roles?*
3.	In what way do you think SDM is important?	*Why or why not?*
4.	What has stopped you from being more involved in SDM in the past?	*How did you feel about that?*
5.	What would make you want to participate in SDM in the future?	*How would this make you more involved?*
6.	What are important things for you to consider when being involved in SDM?	*How do you express these considerations?*
7.	How knowledgeable do you feel about your condition and how to manage it?	*(How) would you like this to change?*
8.	How comfortable do you feel asking HCPs questions?	*What might make you feel more comfortable?*
9.	What kind of information do you think HCPs need to know about you?	*(How) do you make sure HCPs know this information?*
	Intervention ideas	
1.	What kind of health materials have you been given in the past?	*What did you like/dislike about them?*
2.	We are going to develop something to give to young people like you to encourage them to be involved in SDM, what do you think it should look like?	*What format/medium? (booklet, app, video etc)* *What design?*
3.	What information should be included?	*How should that information be presented?*
4.	What would you say to encourage a young person like you to be involved in SDM?	*How would you get the message across?*
5.	What else should be included/avoided?	*What other tips can you give us?*

4.3.3 Qualitative analysis

Narrative inquiry is based on the premise that by listening to the stories of others we can make sense of their experience and understand how they construct meaning within a broader social context (360). Narrative inquiry looks at understanding the meaning within a story, and does not rely on formal analytic steps, allowing for freedom and flexibility of data analysis that may be lost when using other methods. In this case where such individual differences have been found regarding preferences and experiences, it is important to try to avoid overgeneralisation.

The Paradigmatic-type narrative inquiry, or analysis of narratives, outlined by Polkinghorne (360), involves collecting stories for its data and employing paradigmatic analytic procedures to produce taxonomies and categories out of the common elements across the data to produce descriptions of common themes or 'narratives'. It involves moving from stories to common elements (360). Inductive analysis of narratives enables the concepts to be derived directly from the data as

categories described and defined by the researcher, without imposing previous theoretically derived concepts. Paradigmatic analysis is not only used to discover or describe the categories which identify common occurrences within the data, but also to note relationships among categories. This can also enable for comparisons across the sample, for instance between gender or age category.

4.3.3.1 Thematic Analysis

Thematic analysis (225) is an example of a paradigmatic narrative analysis. It enables the development of themes which represent the concerns of the population of interest. I conducted a thematic analysis using Braun and Clarke's (225) approach on the data collected relating to adolescents' narratives and perspectives around decision-making and SDM. This is a six-phase approach involves identifying and analysing patterns, looking at the meaning within the data (Table 11). The significance and meanings that the identified patterns may imply must be considered in attempt to interpret the reality of the participants. Braun and Clarke's (225) approach is not tied to any particular theory, which made it appropriate for this stage of the project since no one particular theory had yet been identified to underpin the PhD thesis, as was outlined in the previous chapter.

The first of the six phases is data familiarisation (Table 11) (225). I transcribed and read through the dataset and listened to the recordings several times to ensure the accuracy of the transcription. This process of 'repeated reading' and listening to the data results in 'data immersion'; a closeness with the data (225). The second step is coding. This involved highlighting interesting and relevant excerpts of data and assigning a label or "code" to capture the idea. Potential themes are generated by grouping codes unified by a central idea in the third phase. In the fourth phase, potential themes are reviewed to ensure theme richness and reflection of the dataset. Phase five involves naming each theme in relation to its central organising construct and writing a definition or description of each. Finally, the last phase is to produce the report.

By following the six phases of coding and theme development, I generated four themes in response to my objectives. This process involved repeatedly reading the transcripts, and coding the entire dataset, which resulted in demarcating common themes. I reviewed and discussed provisional themes with a member of my

supervisory team (NJW), and further refinement of the coding and analysis was undertaken until the salient patterns repeated across and within transcripts were identified and agreed on (225). Initial coding and theme development began after the first 14 interviews. The five subsequent interviews were coded, and no new themes were identified. It was therefore determined that inductive thematic saturation had been achieved (366). Another colleague, a research associate and experienced qualitative researcher in Population Medicine at Cardiff University (DH-H), then double coded 10% of the transcripts independently (n=2), and the outcome of successive discussions resulted in modification of sub-theme names and an additional sub-theme. A thematic map showing the main themes, subthemes and coding has been included in Appendix 4. Data were managed using NVivo 11 qualitative data analysis software (223).

Table 11. Six phases of Braun and Clarke's (225)Thematic Analysis

	PHASES	DESCRIPTION OF ANALYSIS PROCESS
1	Familiarising myself with data	i) Narrative preparation, i.e. transcribing data ii) (Re-)reading the data and noting down initial ideas
2	Generating initial codes	i) Coding interesting features of the data in a systematic fashion across entire data set ii) Collating data relevant to each code
3	Searching for themes	i) Collating codes into potential themes ii) Gathering all data relevant to each potential theme
4	Reviewing themes	i) Checking if themes work in relation to the coded extracts ii) Checking if themes work in relation to the entire data set iii) Reviewing data to search for additional themes iv) Generating a thematic "map" of the analysis
5	Defining and naming themes	i) On-going analysis to refine the specifics of each theme and the overall story the analysis tells ii) Generating clear definitions and names for each theme
6	Producing the report	i) Selection of vivid, compelling extract examples ii) Final analysis of selected extracts iii) Relating the analysis back to the research question, objectives and previous literature reviewed

4.3.3.2 Content Analysis

Using more than one type of qualitative analysis on a dataset has been referred to a multi-method approach (367). A multi-method approach is often used to tackle research objectives from different angles, which avoids pigeonholing which can occur when attempting to use the same methods for more than one objective (367).

In this chapter, objectives (a) (understand experiences and preferences around decision-making roles) and (b) (identify barriers and facilitators to SDM) are both exploratory by nature for which an inductive thematic analysis was deemed appropriate. Objective (c) (intervention suggestions) was much more oriented towards a particular goal, with specific question areas to be answered (e.g., design and format). Content analysis follows a systematic approach, and is best suited to specific research objectives (368). Furthermore, content analysis enables the quantification of common responses. This may be particularly useful to gauge the level of support of different intervention ideas and suggestions, thus potentially improving intervention acceptability and appropriateness for the target audience. A deductive content analysis was therefore conducted on the data collected in the final part of the interviews, which involved asking participants for suggestions around intervention ideas. This involved counting and comparisons of keywords and content related to the predetermined categories (369). Categories for the analysis included design, format, delivery, and content. Interview questions were related to these categories (Table 10).

4.3.4 Positionality

Positionality refers to the positioning of the researcher in terms of social and political background, perceptions and interests in relation to the topic study and the participants involved (370). The position adopted by the researcher affects each stage of the qualitative research process, so it is crucial to be aware of one's position in order to manage biases and assumptions resulting from one's own life experiences or interactions with research participants. This involved analysing myself in the context of the research, reflecting on my own characteristics and previous experiences, and considering how these may have influenced the interviewing experiences and subsequent data gathering and analysis. I did this by documenting my thoughts and reflections in a journal, which enables the researcher to interpret their own behaviours and experiences in a research context (371). In addition to memos that were documented throughout the analysis process, notes were made to record personal reflections such as feelings about the interviews. For example, after my first interview I noted in my fieldwork notebook:

"*Overall went well - participant shared personal information and appeared comfortable. Maybe did not quite share understanding SDM concept, said she was involved in decision-making but when probed said she did not know about options.*

Some difficulty getting started with the life grid, maybe could start with a simple task to get ball rolling without needing too much thought – e.g., numbering years from birth or diagnosis"

Upon reflections of my own assumptions and values; I have always had an interest health and a desire to know what is going on with my body. Since childhood, I have lived with eczema, allergies, and supraventricular tachycardia. My mother insisted on taking me to see naturopaths and homeopaths where I was given treatment which I felt did not alleviate the symptoms. This experience frustrated me, and I wished I had more say in the decisions about my healthcare.

However, it is important for me to acknowledge that others' values do not necessarily align with my own, and I need to be conscious to avoid passing judgement. Although my research focuses on how to increase SDM with adolescent populations, this model of care is not always appropriate for every individual, as some individuals may not always want it. Furthermore, choosing one's involvement level is a form of exerting control, and although this can be challenged, it should be respected.

It was also important for me to be aware of how I may appear to participants. Where adolescents can experience power imbalance between themselves and adults in many aspects of their lives (e.g., school, at home, clinical encounters). As a woman in my 30s I did not want to perpetuate this perceived imbalance during the interview process. I tried to address this in the participatory interview process, iterating that participants have complete control of the extent to which they participate. I also attempted to manage how I may be perceived with my appearance by avoiding dressing overly formally to interviews. At the beginning of the interview, I made it clear to the participants that I was seeking their assistance and was grateful for their time and contribution.

By transcribing interviews simultaneously with data collection, I was able to reflect on my interviewing technique and participants' reactions in order to make improvements as the interviews continued. One example included awareness of my discomfort around silence and a tendency to feel the need to speak when participants were silent. As I recorded in my fieldwork notebook:

"participant was very quiet, particularly at the beginning – lots of one-word responses/ long pauses. I felt uncomfortable with silence and tried to fill it. Need to be aware and attempt not to do this to try not to lead responses. They may just need time to think. Need to try to get past this discomfort – deep breaths".

Allowing the silence can give participants time to consider what they would like to say before speaking. Therefore, in later interviews I attempted to control my impulse to interject or fill silence with non-lexical utterances.

4.3.5 Ethical considerations

Ethical and research governance approval was obtained from the NHS Research Ethics Committee and Cardiff and Vale University Health Board Research and Development Office (IRAS 232192, REC 17/LO/1694). Study documentation including ethical approvals, information sheets, consent forms, invitation letters and reply forms; is included in Appendix 3. One amendment was made to change the value of the voucher offered in appreciation from £10 to £20. This was after a low initial response rate and consultation with two adolescents who suggested a change in the amount and type of voucher to a more favourable brand (Amazon). One older male participant (Gareth) stated "*I'll give this to my mother*" after being offered a Love2Shop voucher, indicating it was not something he could use. Response rate notably improved post amendment. The one responder who had previously received £10 was sent an additional £10 voucher.

4.3.5.1 Interview locations

Due to some interviews taking place at the participants' homes, lone worker issues had to be considered. I ensured that one of my supervisors was aware of the time and exact location of the interview. I would then message the designated supervisor once the interview had finished. If I had not contacted them within an hour, they would contact me to make ensure my safety.

For adolescents requesting to meet in a public location (e.g., coffee shop) parents of those under 16 years would need to be present at the establishment. I would select a table as far away from other customers and workers as possible in attempt to ensure that the interviews could not be overheard by patrons and employees. I suggested it would be beneficial to hold the interview without the parent within earshot but did not insist if this were preferable to the parent and participant.

4.3.5.2 Participant safety and well-being

Pseudonyms were used in the report, and potentially identifiable minor details were changed for confidentiality purposes. This was to prevent deductive disclosure due to names or characteristics mentioned, such as clinical team members or a particularly rare condition. The research involved collecting data from people about themselves and their experiences from a vulnerable population. Although risk to the participants was considered minimal, issues such as anonymity, safety and emergence of sensitive issues needed to be taken into consideration.

The questions included in the interview schedule were not deemed overly sensitive, with a focus on experiences of decision-making in clinical encounters. However, participants were free to discuss what they wanted, and therefore there was the possibility of disclosing information which they may have found distressing. Furthermore, speaking about diagnosis and dealing with a LTC could be unpleasant for the participants. Participants were informed orally and in writing that they could skip any question that they wanted and terminate the interview at any time. They were also encouraged to speak with a member of their clinical team about any issues which arose. This was stated on referral sheets which were given to all participants at the end of the interviews, which also included my contact details should they have any questions or choose to withdraw from the studies, contact details of a research associate at Cardiff University who was not involved in the study should they want to make a complaint, and contact information for ChildLine should they want to discuss any emotional issues (Appendix 3.19)

4.3.5.3 Adolescent advisors

The adolescents involved in piloting of the information sheets, consent forms and information sheets were determined to be acting as research advisors as opposed to participants. According to the NHS Research Health Authority, involving the public in the design and development of research does not generally raise any ethical concerns and therefore does not need to undergo an application for ethical approval, but should be stated on the Research Ethics Committee application for the later research to be undertaken (372). However, there is still a duty of care to involving the public in research, particularly more vulnerable populations such as minors. The same principles of informed consent, confidentiality and right to withdraw need to be considered (185). This involved clarifying to the adolescents exactly what

participation would entail (i.e., providing feedback on research documentation and interviewing techniques), and that the adolescents were free to participate to the extent they wanted and withdraw at any time. Parental consent was sought for the 15-year-old. Apart from age and sex, no personal data were retained, and nothing was audio recorded during the meetings. Dietary restrictions were checked and refreshments were provided at meetings, which can provide sense that their time is valued and respected, as well as helping to break the ice (373).

4.4 Results

4.4.1 Participant response

All the eligible potential participants who were identified by a member of their clinical team agreed to being approached by me. There was a wide variation between the clinical teams in terms of team members and patient support. For example, adolescents attending the endocrinology clinic could see a consultant, dietician, clinical psychologist, specialist nurse or youth worker, whereas those attending the neurology clinic tended to only meet with a consultant and specialist nurse.

All but one potential participant expressed interest in the study after being approached, and 29% responded by returning the consent to contact form in the self-addressed envelope included in the packs provided to all interested potential participant. A summary of approached and recruited participants can be found in Table 12. A sample of nineteen adolescents between the ages of 13 and 19 (mean + SD = 16 ± 1.9) years was recruited (Table 12). Characteristics associated with each pseudonym are included in Table 13. Due to the inclusion of participants with rare conditions, the specific conditions are not named to preserve anonymity. Interviews took place between December 2017 and July 2018. Parents requested to be present in the room on two occasions (Jasmine and Alice).

Interviews ranged from 20:04 to 57:25 (Mean+ SD =35:35± 10:06, Median =34:31) minutes. Some participants freely provided detailed information using the life grid, whereas others were more hesitant, even with prompting. The presence of parents in the room (n=2) did not appear to affect the participants' disclosure around their views and experiences. In one case the mother and daughter did not converse in English. Themes identified from the interviews were not found to differ between genders, ages or LTCs. Although holding interviews in a public place could affect participants'

willingness to disclose personal information, the location of the interviews also did not appear to influence the interview dynamic as I did not observe any difference in hesitance or reluctance in sharing personal details due to location. This could be because participants were asked to select a location where they would feel most comfortable conducting the interview, and in all instances where interviews were held in a public place we were far away from any other people.

Table 12. Recruitment summary

		Adolescents Responded N=19	Adolescents Approached N=66
Sex:	Female	N=14 (74%)	N= 36 (55%)
	Male	N= 5 (26%)	N= 30 (45%)
Age range:	13-15	N=9 (47%)	N= 31 (47%)
	16-19	N=10 (53%)	N= 35 (53%)
	Mean + SD	16 ± 1.9	16 ± 2.2
Time elapsed since diagnosis (years):	Range	1 to 18	-
	Mean + SD	7.2 ± 4.8	
Recruitment clinic:	Neurology	N=6 (31%)	N= 20 (30%)
	Endocrinology	N=7 (37%)	N= 20 (30%)
	Rheumatology	N=2 (11%)	N= 8 (12%)
	Nephrology	N=4 (21%)	N= 18 (27%)
Ethnicity:	White	N= 15 (79%)	-
	South Asian	N= 3 (16%)	
	Black	N= 1 (5%)	

Table 13. Participants

Participant Pseudonym	Age (years)	Clinic recruited Paediatric (P)/ Transitional (T)	Elapsed time since Diagnosis	Gender	Interview Location
Miriam	15	Endocrinology **P**	7 years	F	Hospital site
Alice	15	Neurology **T**	13 years	F	Participant's home
Rhys	14	Rheumatology **P**	11 years	M	Participant's home
Kayleigh	15	Neurology **T**	6 years	F	Participant's home
Laura	18	Nephrology **T**	2 years	F	Hospital site
Joe	17	Endocrinology **T**	2 years	M	Participant's home
Melissa	19	Nephrology **T**	4 years	F	Hospital site
Caitlin	18	Neurology **T**	15 years	F	Café indoors
Stephanie	15	Neurology **T**	6 years	F	Café indoors
Jessica	14	Rheumatology **P**	3 years	F	Hospital site
Bethan	18	Nephrology **T**	18 years	F	Shopping centre food court
Gareth	19	Nephrology **T**	10 years	M	Café outdoors
Susie	16	Neurology **T**	5 years	F	Participant's home
Jasmine	15	Endocrinology **P**	1 year	F	Hospital site
Adam	13	Endocrinology **P**	13 years	M	Participant's home
Lydia	15	Endocrinology **P**	5 years	F	Participant's home
Lisa	16	Neurology **T**	5 years	F	Hospital site
Sam	18	Endocrinology **T**	5 years	M	Hospital site
Sophie	19	Endocrinology **T**	6 years	F	Hospital site

4.4.2 Themes and subthemes relating to barriers and facilitators around shared decision-making

Many participants were able to identify explicit barriers to and/or facilitators of their involvement in SDM. They also discussed such influences more implicitly when describing their experiences with decision-making during consultations. Participants each described between one and three clinical decisions (Table 14). Most of the decisions that participants described concerned initiating or changing treatment (67%). Although over half of the experiences of ('*real*') decision-making were said to have reflected participants' preferred involvement roles (59%), in many cases there was a mismatch between involvement preferences and experiences, where mostly participants would have preferred more involvement in the decision-making.

The analysis resulted in a final analytic structure of four themes and nine subthemes which describe barriers and facilitators around SDM (Appendix 4, Table 15). The quotations used to illustrate the themes are followed by participant pseudonym, age, clinic recruited, and elapsed time since diagnosis.

Table 14. Decisions described using pie charts

Number of decisions disclosed	
Total	N=39
Range per participant	1 - 3
Mean + SD	2.1 ± 0.7
Mode	2
Types of decisions	
Begin treatment (e.g., insulin, anticonvulsants, analgesics)	N=15
Change type/dosage/frequency of medication	N=11
Change method of medication administration (e.g., from insulin injections to pump)	N=4
Lifestyle changes (e.g. diet, exercise)	N=4
Discontinue medication	N=3
Undergo Surgery	N=1
Participate in a clinical trial	N=1
Adolescents' preferred (ideal) compared to experienced (real) involvement roles in decisions	
Adolescent's preferred role was equal to their experienced role	N= 23 (59%)
Adolescent's preferred role was larger than their experienced role	N= 14 (36%)
Adolescent's preferred role was smaller than their experienced role	N= 2 (5%)

Table 15. Themes/ subthemes, their description, and exemplar quotations

Themes/ Subthemes	Description	Exemplar Quotes
Interactional dynamics within the triadic relationship		
HCPs' communication approach	HCPs either invite or prevent SDM involvement in the way they interact with adolescents and parents.	*"They [HCPs] will ask you questions sometimes, but we need to be encouraged to ask questions, not just sit there and listen. But they mostly talk to my parents, they talk to my parents more than they talk to me."* (Jessica, aged 14, rheumatology, 3 years)
		"They [HCPs] speak to me, so I speak back. I never used to …. But now they've started speaking to me, I started speaking back" (Rhys, aged 14, rheumatology, 11 years).
Parental support of adolescent involvement	Parents' support can facilitate involvement; however, they often inhibit involvement by 'taking over' during consultations.	*"Probably just telling my mum to stop talking, it's difficult with her speaking all the time for me to speak as much as I think I should. I could probably ask her not to come in with me and she'd probably be ok with it. It would probably be much better cuz I could speak to him [HCP] and say like, yeah more stuff what I feel. They [HCPs] normally speak to both of us, but my mum normally is like: "Yeah, she's doing this, she's doing this, she's doing this" it's like mum, let me speak.* (Bethan, aged 18, nephrology, 18 years)
		"I don't mind my mum helping if I forget something, but I liked it being able to speak myself in my appointment the other week. I prefer her to just be there to help, and me be the main person the doctor speaks to." (Kayleigh, aged 15, neurology, 6 years).
Power imbalance	Adults are often seen as having more authority over the decision-making process.	*"I'm just happy to sit back and let them (adults) say what they want because obviously they know better."* (Adam, aged 13, endocrinology, 13 years)
		"I really didn't have much of a say in it because I was under 18 so it wasn't my decision, it was basically down to the doctor and my mum." (Gareth, aged 19, nephrology, 10 years)
Expression of autonomy		
Sense of agency	Adolescents feel they "should" be involved in decisions that affect them.	*"It's cuz obviously it does affect me at the end of the day, so I'd like to be involved as well as the doctor cuz, I dunno, it's my condition at the end of the day. I mean, I know it's diabetes, but everyone's diabetes is different, so I probably know my own a bit better than the doctor does. Just because you know yourself, and you know what's…you need to really, especially after you've had it for a while."* (Jasmine, aged 15, endocrinology, 1 year)
		"Well, like it's important, it's your body, you need to have a say. Of course, the doctors are the experts, but you know your body. They don't know how it feels to be you and live with it, and the effects." (Rhys, aged14, rheumatology, 11 years)
Sense of empowerment	Adolescents need to feel they have control over the processes. Some adolescents disengage from	*"I understand they [doctors] have to say that, but there is times where it drags on to the point where I'm like: "Now you've said all this, I really don't want to do it, just because I'm so tired and bored of hearing it."* (Adam, aged 13, endocrinology, 13 years)

	discussions, and make decisions as a reaction to a perceived loss of control.	*"I shoulda taken it, but it's, you're so in your own head about being like: 'Nah, no thank you' that you don't do it at that time, you just pull a strop. So, yeah, so I regret that a bit, abut as in like I felt in that moment I was a bit like: 'Well, I get a say in this' so I'm happy about that because I said 'no' I didn't follow through with whatever they told me, so it was like, can't listen to your doctor all the time, even though you should, there's moments where you just don't"* (Susie, aged 16, neurology, 5 years)
Belief around own ability and value of contribution		
Perceived adequacy of own knowledge and skills	Adolescents' self-efficacy around involvement in discussions and decisions influences their actual involvement.	*"Cuz some of my things come out like daft, I come out with daft things. Or I'll be about halfway through a blooming sentence and then like I've forgotten what I'm going to say, and we've got a finish with that conversation."* (Stephanie, aged 15, neurology, 6 years)
		"Naivety. Just not knowing what, I wouldn't know what I was talking about, um the medications and stuff like that. I wouldn't know what to discuss. I don't know." (Rhys, aged 14, rheumatology, 11 years)
Perceptions around involvement outcomes	How adolescents perceive possible outcomes, including benefits and risks, of their involvement in SDM affects their attitudes towards being involved.	*"if they* [patients] *are involved they will know what's going on and then they can learn more"* (Sam, aged 18, endocrinology, 5 years)
		"Sometimes I think people don't do it [participate] *because they're scared of what the outcome's gonna be if they put forward their decision"* (Jessica, aged 14, rheumatology, 3 years)
Navigating personhood identity and patienthood identities		
Endeavour for normality	Adolescents do not want to feel different, which can cause them to disengage during discussions. Contact with other young people in similar situations provides support and allows them to feel more "normal".	*"Also, I think would happen if people, like you know the same ages, someone a year older or uh two years older or the same age as me has like a different illness, and say they have epilepsy and I have diabetes, we can speak about the similarities to it, and the differences to it, like how it affects you cuz I think speaking with someone your age, sometimes friends are not enough, and sometimes talking with a stranger, not a stranger, but talking with someone with your type of thing helps."* (Miriam, aged 15, endocrinology, 7 years)
		"dunno maybe you do feel like it's a little bit unfair like, cuz obviously like you've gotta go to school with kids that don't have it and stuff, and then it's like just a bit unfair so like then you're in that mind-set and then you just, you didn't even, you can't be bothered asking things, stuff like that." (Sophie, aged 19, endocrinology, 6 years)
Readiness to be involved	Adolescents need to feel ready to be involved in SDM. This usually develops over time from diagnosis. Readiness includes mental and physical well-being. Lack of readiness can lead to avoidance and incite fearfulness.	*"I dunno, I just got too nervous when they were talking about it, because like a lot of people don't like going into hospital, just nervous about just having to be there and didn't want to think about it"* (Alice, aged 15, neurology, 13 years)
		" with this type of disease that can alter my life or whatever um and maybe just like a small amount of information at first so that, I don't know, people didn't get too panicked" (Melissa, aged 19, nephrology, 4 years)

Participants spoke about how the dynamics between the adolescents, parents and HCPs strongly influence adolescent involvement in SDM.

4.4.2.1.1 HCPs' communication approach

Participants described how the way HCPs communicate with parents and the adolescents can either endorse or dismiss adolescent involvement in the decision-making process. Adolescents said that clinicians' behaviour that invites and encourages their involvement includes asking and inviting questions; speaking directly to the adolescents instead of the parents; information provision, including presenting treatment options; and providing adolescents with enough time to consider the options so that they do not feel rushed. As Jessica (aged 14) stated: "*I would like them [doctors] to speak to me because it makes me feel like I'm actually there*". Adolescents acknowledged feeling more comfortable when HCPs communicate in a manner that is perceived as friendly, which can encourage involvement.

"*Sometimes it helps when the doctors are like nicer. Like when the doctors are friendly and stuff, then you feel more at ease to talk to them. Whereas if it just feels like they're bored or like, they're like really serious, it's kind of like hard to speak*" (Sophie, aged 19, endocrinology, 6 years).

Adolescents, even those who said they play a large role in decision-making, reported being provided insufficient information surrounding treatment options, which limited their ability to be involved. Some adolescents said they felt that HCPs are too busy to explain their condition or treatment options in detail.

"*I don't feel like I've had it properly explained by the doctor, cuz obviously you've got time slots cuz more people need to come and see. They can't spend all day telling you about it.*" (Sam, aged 18, endocrinology, 5 years).

In addition, some adolescents said they felt they could not approach HCPs for information about behaviour which may be disapproved of, which could result in seeking advice elsewhere.

"*I feel like at this age, even though we're all underage, 16-year-olds are still out drinking. But the doctors, even though they probably know this, will never give you information on how it had to, how it reacts kind of thing, so then I have to look it up myself.*" (Lisa, aged 16, neurology, 5 years)

4.4.2.1.2 Parental support of adolescent involvement

Participants said they often feel that their parents' roles in decision-making should be less than they actually are, and that parents should play more of a supporting role.

"They [parents] *should just like advise me mostly, because I know it's about me"* (Jessica, aged 14, rheumatology, 3 years)

Adolescents noted that parents can support their involvement by filling in missed gaps of information provided by adolescents, and helping adolescents to process and remember information provided by HCPs. However, adolescents said that their parent(s) often limit their involvement by not allowing them the opportunity to speak.

"My mother takes over, because she thinks she can have more of a say than I do cuz she's the mother….she should just stand back and let me talk, say in my opinion." (Bethan, aged 18, nephrology, 18 years)

Adolescents noted that having parents present in the consultation can sometimes cause unwillingness to share certain information of a sensitive nature.

"No offence to any parents, but having the parents out of the room is a massive relief because it just is, and if you feel confident enough to talk about it, but typically in the Asian minority, if you speak something and you don't want your parents to hear it, they're, they're not gonna get disappointed but in a way they're gonna feel some kind of guilt or like 'why didn't I help them'" (Miriam aged 15, endocrinology, 7 years).

4.4.2.1.3 Power imbalance

Adolescents indicated in the pie charts that they mostly would like a nearly even three-way split between themselves, parents, and HCPs, usually allocating slightly less of a say to parents. However, the adults (parents and HCPs) were said to often have more influence over the decision-making process, and that their contribution may be more valuable. This perceived power imbalance between the adolescent and the adults was said to cause adolescents to feel that the others have, and possibly should have, more authority over decisions.

"They [HCPs] are generally just talking to the adults, looking at the adults and not me…. I know why they do it mostly cuz, you know, they're adults, they get the most attention really" (Jessica, aged 14, rheumatology, 3 years)

Some adolescents said they felt they were not "allowed" to be involved in the decision-making. As Alice (aged 15) stated:

"Well, if I'm the patient I should be involved in it all, I don't think there's any chance I could get involved because it's their job, like I don't know where I come into it because they know more than me"

Furthermore, adolescents spoke about times when they had been reprimanded by adults during clinic appointments for less favourable self-management results, such as high HbA1c levels (diabetes), which could lead to feelings of guilt and reluctance to engage.

"She [doctor] *was really strict and was like: 'we need to get this* [glucose levels] *under control' and this that and the other, and then like yeah, talking about all kinds of risk factors and all this sort of stuff. I'm just like: 'what, is this like my fault?', just didn't wanna know"* (Lydia, aged 15, endocrinology, 5 years)

Some adolescents described having too many adults in the room during clinical encounters as overwhelming. As Lisa explained, she was merely told who would be present during a consultation but would have liked to be given the option.

"it's like everyone's all gathered…. if I had one-on-one with my actual consultant, I recon it'd be nice, but it feels like you don't get that opportunity cuz the nurse takes notes, the little student takes notes, the doctor takes notes, and there's just notes everywhere." (Lisa, aged 16, neurology, 5 years)

4.4.2.2 Expression of autonomy

Overall, adolescents with LTCs reacted positively towards the concept of SDM. They said they value being involved, and want a sense of control over their lives, and decisions that affect them.

4.4.2.2.1 Sense of agency

Adolescents expressed ownership over their bodies and their health. This subtheme represents the abstract concept that adolescents with LTCs feel they should be involved, and that it is their right to be included in the decision-making process, which facilitates SDM. This was often voiced during the interviews.

"Um I think you should be allowed to make any decision you want really. Because it's you as a person, it's not them, they're not going through it" (Susie, aged 16, neurology, 5 years)

Several adolescents stated that they know about their own lives and bodies better than anyone else, and therefore feel that it is vital that they have a say in decisions which are relevant to them. As Jessica (aged 14) stated: "*It's me, it's my body, I know what's best"*

However, many adolescents acknowledged that they are not, and have not been as involved in the decision-making processes as they should be.

"I dunno, I suppose it's my body, and I have to deal with the consequences so I should probably have more of a say" (Joe, aged 17, endocrinology, 2 years)

4.4.2.2.2 Sense of empowerment

This subtheme represents the experience of having, or not having, a sense of control over the healthcare decisions, and decision-making process. Adolescents noted that when they feel they have control over what is happening to them, they react positively towards being involved in discussions and decisions, which can facilitate SDM.

"I really felt like I was being in control of myself then. And I could give my opinion on what was going on" (Stephanie, aged 15, neurology, 6 years)

Several adolescents spoke of their reactions to feelings of powerlessness and perceived loss of control. Some said this led them to refusing to engage in discussions, sometimes taking complete control over a decision as a consequence.

"*when I come off medication for like a year, that was all my own decision, and they* [HCPs and parents] *didn't really have an option, I didn't let them have an option cuz I was like 'no I don't wanna be on that' I just like refused it*" (Caitlin, aged 18, neurology, 15 years)

Reports of autonomous decision-making on the part of the adolescent were the only decisions for which participants indicated in the pie charts that they should have had a lesser role.

"I felt like, at the time I was like: "Ha, I've got the final word in this, you can't force me into it" kinda thing. Um, so I just felt a bit like: "Well, it's me who's gotta do it so you can't force me into it". Um but looking back, I shoulda done it, I shoulda listened to the adults, so I kind of regret trying to be all high and mighty" (Lisa, aged 16, neurology, 5 years)

Miriam (aged 15) expressed feelings of empowerment, and intention to be more involved in decision-making as a result of the participatory interview process.

"Actually, I'm old enough to make my own decisions, I shouldn't have someone else making them for me, as in like they can make some decisions, as in what I'm allowed to do and what I'm not allowed to do, but I'm fifteen, I'm allowed, I should be allowed to do what I want now, so I can and I will express myself, like. I think now from this [pie chart] *I see that, and I want to have more say in stuff."*

4.4.2.3 Belief around own ability and value of contribution

This theme focuses on adolescents' evaluation of their involvement in different aspects of SDM. The concept of a "good" or "right" decision often arose in discussions.

4.4.2.3.1 Perceived adequacy of own knowledge and skills

Participants spoke about self-efficacy regarding several aspects of involvement; including their knowledge and understanding of their condition and management options; asking questions; remembering information; involvement in discussions; and making a "good" decision.

"*You have to be confident it, you actually, you need to be confident. You need to know what you're on about, so you have to do your research and make sure it's, you know what's best for you*" (Sam aged 18, endocrinology, 5 years)

Insufficient understanding surrounding their condition and treatment options was the most mentioned barrier to SDM. There was no apparent relationship between self-efficacy and participants' age at the time of interview, however, many expressed that their confidence increased as they gained more experience living with their condition, which enabled them to become more involved in discussions and decision-making.

"*I dunno, I think just cuz I'm older, and at the time I didn't really know very much about diabetes, so I kind of didn't feel like I could say what I wanted cuz I didn't want it to be like a little bit wrong or something silly, if that makes sense. Now I feel just a little bit more confident because like obviously I've had it for years, so I kind of do know.*" (Sophie, aged 19, endocrinology, 6 years)

Fear of saying something "wrong" or asking a "stupid" question is a common sentiment, which adolescents said prevented them from being involved.

"*Sometimes I don't understand what's going on, but I feel like if I ask a question, I might sound kind of stupid, um they're like kind of basic questions, you know like normal questions, yeah stuff like that. Maybe I shouldn't ask them because they're too basic*" (Kayleigh, aged 15, neurology, 6 years).

Perceived capability to remember, both what to say and what has been said also influenced involvement.

"*My memory is horrendous. I prefer my mum to say it, so I don't miss anything out.*" (Lisa aged 16, neurology, 5 years).

4.4.2.3.2 Perceptions around involvement outcomes

This theme represents the perceived benefits and risks around SDM involvement. Treatment preferences and values vary between individuals. Sophie (aged 19), for example stated:

"*if you take four injections a day, you can eat more or less what you want within, it gives you so much freedom cuz you don't have to eat every day at a set time, which means you can go and do more things and everything like. And that was quite*

important to me cuz I was in school and stuff and I didn't wanna go and like do different stuff from my friends and stuff"

Some adolescents identified the importance of adding their input to discussions and decisions to find the treatment that best suits them, and to best understand what is happening to them.

"I think if I was more involved in the decision, I could take more ownership over my self-management." (Joe, aged 17, endocrinology, 2 years)

However, adolescents did not always acknowledge the importance or benefits of their contribution. Some said at times they did not feel interested or motivated to be involved, and often believed doctors to hold the knowledge about what is best for them.

"*You just really, just have to go along with* [treatment] *because the doctor's right, end of story really."* (Gareth, aged 19, nephrology, 10 years)

4.4.2.4 Navigating personhood and patienthood identities

This theme represents the conflict of identity between patient versus self that adolescents with LTCs can experience. This conflict can cause them to move between accepting their LTC, and disconnecting from, or avoiding the fact that they have the condition. This can lead to disengagement from healthcare discussions and decisions.

4.4.2.4.1 Endeavour for normality

The importance of trying to maintain as normal a life as possible was highlighted by many of the adolescents in the interviews. Adolescents often compared their current lives to before diagnosis, and strive to regain that sense of normality.

"*I was really ill, but then it, you know, it paid off then after the cycle finished, after the six months I could do everything which normal teenagers do, go out, climb trees, break arms, break legs….. Until you had to go back for treatment again"* (Gareth, aged 19, nephrology, 10 years)

Some adolescents acknowledged that involvement in healthcare decision-making can assist with the selection of a treatment plan which helps them to regain normality, such as changing from insulin injections to an insulin pump.

"*I think I'd say that in order to get your life back to the most, back to how it was in the best way you can, you have to be involved. Because nobody else knows what it was like before, and nobody else knows what it's like now apart from you. And how's a doctor gonna make that decision for you?"* (Sophie, aged 19, endocrinology, 6 years)

Feeling as though they can be "normal" teenagers alongside their LTC was said to help adolescents accept their condition, and could allow them to engage and be involved in SDM. However, adolescents might not want to be involved in discussions and decisions during consultations because they prefer not to be reminded of having a condition which sets them apart from others. Adam (aged 13) spoke about how he did not want to be labelled by his condition as he stated: "*I'm not a diabetic, I just, my pancreas don't work*"

Some adolescents spoke about having friends with LTCs. Having contact with other adolescents with LTCs was said to help adolescents maintain feelings of normalcy:

"*If you're meeting people who have got similar health conditions to you, or experience health conditions in general, you can get out with them, you can talk with them, see how they're feeling, what they've experienced, and I think that's a really good way to also influence you to um, you know, talk about your decisions because you know then what other people have done, and what they've been through, knowing that you're not alone.*" (Laura, aged 18, nephrology, 6 years).

Three participants with neurological conditions noted that they had never met another person their age with the same condition, about which they expressed feelings of loneliness. One of these participants with a particularly rare condition stated that she felt uncomfortable explaining her symptoms to people.

A key difference in the transitional neurological clinic is the absence of youth workers. Youth workers in the renal and endocrinology clinics engage with the adolescents in the waiting room and invite them to organised events where they can meet other adolescents with similar conditions. Gareth (aged 19), who has a renal condition, spoke about the benefits of these meet up groups including shared experiences:

"*everyone can just go and meet and just hang out, you know talk to everyone you know, discuss what's happened with them, someone else will say what's happened with them, and they'll sort of start sharing stories really … where people can just get together at the same time be normal and talk about their problems with someone else who they have the same problem or something different and they can share stories on how, how they felt um how they still feel, how they manage it, how it sort of in a way to an extent has it taken over their lives, does it make them look at life through a different view, so hearing from people in similar situations to them.*"

All participants with neurological and rheumatological conditions stated that apart from online forums, they were unaware of any form of support group in their area.

4.4.2.4.2 Readiness to be involved

The concept of readiness described by adolescents with LTCs refers to feeling equipped and in a fit position to be involved. Feelings of readiness to be involved in decision-making could depend various factors. For example, at the time of diagnosis, adolescents described not feeling ready to be involved, finding it difficult to process information, and therefore stated a preference for less involvement.

"you're shocked cuz you've obviously just been diagnosed and then it's hard to take in so much information because it just feels like it's been like forced on you, obviously you've gotta learn it, but there's just a lot to take in at that time…..now I feel just a little bit more confident because like obviously I've had it for years (Jasmine, aged 15, endocrinology, 1 year)

However, apart from at diagnosis, all adolescents expressed a desire to be involved in decisions to some extent. Acceptance of their condition was said to be necessary for adolescents to feel ready, and more likely to be reached as the longer they experience living with the condition. Readiness was also said to influence self-efficacy around involvement.

"*As I get older, I get more confident, so I think it, I do more talking when it comes to other appointments in the future*" (Susie, aged 16, neurology, 5 years)

Adolescents said they need to feel emotionally ready to receive certain information and be involved in certain discussions and decisions. Involvement when adolescents do not feel ready can lead to avoidance and fearfulness.

"I dunno, I just got too nervous when they were talking about it…. and didn't want to think about it" (Lydia, aged 15, endocrinology, 5 years)

Three adolescents also spoke of experiencing mental health issues as a result of their condition or side-effects of medications. Both physical and mental well-being were said to influence how ready adolescents felt to be involved during a given consultation: "*I feel like whether I want to be involved it's just depending how I feel, what kind of mood I'm in on the day*" (Lisa, aged 16, neurology, 5 years)

4.4.3 Content Analysis around intervention ideas

Many participants seemed to have difficulty generating ideas for an intervention to promote SDM, which was described as 'health materials' in the interview. Participants often answered "*I don't know*" or "*I'm not sure*" to the questions in this part of the interview. However, most were able to describe a programme or leaflet

they had received in the past and were able to describe factors that they appreciated or did not like. The results of the content analysis are summarised in Table 16.

Table 16. Summary of Content analysis for intervention ideas

Intervention Suggestions	Number of participants
Format/Delivery	
Booklet	N=12
Mobile app	N=3
Video	N=2
Poster	N=1
Design	
Minimal writing	N=13
Pictures/diagrams	N=12
Colourful	N=8
Text bubbles/boxes	N=4
Bullet points	N=4
Content	
Uncomplicated and informal language	N=14
Positive messages	N=9
Stories of other patients	N=6
Age appropriate	N=5
Where to find more information	N=4
Catchy title	N=3
Facts	N=3
Tailored to the individual	N=2
Fun	N=1
Immediate Benefits	N=1

4.4.3.1 Format and delivery

Most participants were able to express suggestions for intervention format, (n=18) the most popular being a booklet/leaflet (n=12). However, one participant stated that "I wouldn't, can't think of any other reason I would pick up a leaflet other than nothing else to do" (Rhys, aged 14). Other ideas included a mobile app (n=3), a video (n=2) and a poster (n=1). Forms of interventions adolescents stated they had previously received were most commonly booklets/leaflets, and those attending the endocrinology clinic had attended educational programmes. Many participants said that clinic attendance would be the best time for them to receive the intervention, particularly during the time they are waiting to see members of their clinical teams. One other suggestion included having the intervention available in schools in the form of a poster on a noticeboard.

4.4.3.2 Design

Many participants spoke of receiving materials which they had found "boring" and uninviting. These included insufficient colour and too much text. The most common design suggestions included minimal writing (n=13), images (n=12), being colourful (n=8), including bullet points (n=4) and text bubbles and boxes (n=4).

"*I think something that can catch your eye probably. Bright, anything really to just balance with the writing, the information as well. So, like bubble writing, different fonts, colours. Things that are eye-catching.*" (Jessica, aged 14, Endocrinology, 1 year)

4.4.3.3 Content

Participants emphasised that content should be uncomplicated, to the point, and age appropriate. As Alice (aged 15) stated:

"*You need something that's like, someone my age would, 15-year olds would actually understand, that's straight forward and is to the point. So, we kind of understand in our own way, not just adults' way*".

Adolescents also expressed desires for an intervention which was positive and fun. Suggestions for content included real patient stories, interesting facts, and positive messages. Such messages included being confident to express opinions, and that the adolescents' opinions are important.

"*So maybe like the writing on the font, like the caption on it should say something like: 'don't be afraid to speak out' and maybe a photo of somebody speaking out, perhaps if people spoke about their experiences in there as well, and how they were afraid to speak out but then they did it in the end, and how it helped them.*" (Bethan aged 18, nephrology, 18 years)

4.5 Discussion

4.5.1 Summary of findings

This study provides insight into adolescents' perceptions around decision-making involvement by focusing on their lived experiences during consultations. In line with findings from Chapter 2, nearly all the adolescent participants indicated a desire for the same or greater involvement in the decision-making process, particularly as they gain more experience with their condition. What this chapter adds is adolescents' perceptions relating to hindering and motivating factors around SDM participation. Adolescent-reported barriers and facilitators to SDM relate to interactional influences, and evaluations around SDM in line with their self-efficacy and sense of self. The adolescent participants often relayed contradictory perceptions around their

roles and involvement. They grapple with feeling that it is their right, and that they should be involved in decisions that affect them, but that doctors are the experts, and they are worried about making the "wrong" decision. HCPs' behaviour can improve adolescent involvement by ensuring they speak to patients directly, providing sufficient information about options, inviting questions, and making it clear that they want them to be involved. Parents can support their son/daughter's involvement by helping them to remember information and "fill in the gaps", and encouraging them to ask and respond to questions. Other facilitators for SDM include having favourable context, positive evaluation, feeling able and ready, and having some sense of actual control alongside their developing identity and perceptions of what is "normal".

4.5.2 Strengths and limitations

Although I attempted to recruit an equal number of male and female participants, more responders were female. This responder gender bias has been reported in other qualitative studies with adolescents with LTCs (164, 270). However, themes identified from the interviews were not found to be distinct between male and female participants. With a low participant response rate there may be sampling bias, with those who are more willing to be involved in qualitative health research possibly taking a more proactive approach to involvement in healthcare decisions. However, there was a range of engagement and forthcomingness during the interviews, which is reflected in the duration of interview recordings.

The process of completing life grids and pie charts may have been deemed complicated by some adolescents, and may have required a reasonably high level of literacy. This could potentially exclude participants with lower literacy levels, who may be in particular need of support. I tried to address this issue by clarifying that the life grids and pie charts were optional, and that participants could just answer questions if they preferred. In the instance of one participant (Bethan) I was asked to complete the activities on her behalf as she stated she could not write, which involved her indicating what she wanted me to write and where. This was seemingly as effective in eliciting the participant's narratives as when they completed the activities themselves.

A booklet was the most recommended medium for the intervention, which may be the result of availability heuristic, due the fact most participants had received paper-

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based health materials previously. It could also be that the term 'health materials' might be associated with a paper form, resulting in response bias. However, 'health materials' had been piloted and agreed to be the most appropriate term, as the term 'intervention' was associated with when friends and family members intervene to encourage a loved one to get help with an addiction (e.g., drugs or alcohol). Furthermore, if participants struggled to think of a possible medium for health materials, I offered suggestions including a mobile app, video, educational session, and booklet. Only one participant was unable to suggest any medium for delivery.

This study may have benefited by eliciting participants' understanding of SDM as opposed to providing a definition of the concept. This could have been done by asking participants "What do you understand by SDM?". This would enable participants' to provide their own definition, thus improving accounts of their narratives and lived experiences. It could also have been useful to help identify where participants' perceptions of SDM did not coincide with the literature. For example, Miriam (a 15-year-old diagnosed with type 1 diabetes seven years previously) stated she had been involved in SDM, but when asked about how options were communicated to her by HCPs, she responded that they had not. When exploring barriers and facilitators to SDM in adolescent mental health, Hayes and colleagues (144) asked for participants' definition of SDM at the beginning of interviews, and for those who did not know what SDM was or whose definition was incongruent with literature definitions, SDM was clarified as '*being involved in care and treatment decisions*'.

Although adolescents were involved as advisors in piloting the research documents and interview techniques, and techniques were selected to enable participants to take control over some of the interview processes, this study could have benefited from a stronger element of co-production. This convenience sample of adolescent advisors did not include adolescents with any disclosed LTCs. In addition, as they were already known to me, they may share a similar world view, which would prevent the acquisition of more diverse perspectives. It may have been more appropriate to include a group of adolescents with LTCs as co-researchers from the beginning of the research process. Adolescents with LTCs could have been brought together to form an advisory group to inform the research design process from the beginning, putting more of an emphasis on working with adolescents as partners in

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research as opposed to merely collecting data from them. This mirrors the key principles of SDM. For example, McAnuff and colleagues (183, 184) set out to co-produce an intervention to support adolescents with neurodisability to participate in leisure activities. Adolescents with neurodisability were involved from the beginning in identifying and prioritising the research topic and preparing the initial funding application. A group of eight adolescents and researchers then co-produced the data analysis, interpretation, and dissemination. This resulted in the use of creative methods, such as the use of creative arts to disseminate the message which, although an unfamiliar approach to the researchers, was natural and interesting for the adolescents. During the analysis stage, adolescents' views challenged the research team to consider whether and how the study results might help to address issues experienced by adolescents living with neurodisability.

Had I taken a more participatory approach to this research, I would have been better able to ensure that the reported results accurately represented the narratives of adolescents with LTCs and were disseminated in a fashion which would be interesting to, and understood by this population. Although co-production is characterised by uncertainty and working in ways which are unfamiliar to most researchers, this flexible approach enables researchers to move away from rigidly following pre-determined protocols to enable a sharing of understanding and power over the research process, allowing researchers to really learn from the population of interest, for whom, such as in this case, the intervention is being developed (183, 184, 374, 375).

Despite these limitations, there are considerable strengths to the study. The use of participatory methods proved effective in eliciting and representing young people's perspectives and biographical narratives. The use of pie charts is a method that has been employed successfully in previous studies exploring adolescents' roles and preferences in the decision-making process (239, 376). However, this study differs in its focus on possible reasons for the discrepancies between the real and desired roles, and potential enablers of involvement. This enabled the identification of perceived barriers and facilitators to SDM. The life grids afforded the respondents a degree of control over disclosure of sensitive issues. In previous studies this has been found to alter traditional interview dynamics in attempt to address the potential issue of perceived power imbalance between the researcher and participant (364,

365). This may be particularly important for adolescents, where perceived power and control are strong influencers of involvement.

4.5.2.1 Potential ethical issues

Providing financial incentive to participate in the form of gift vouchers may instigate extrinsic motivation to participate from an external source, as opposed to intrinsic motivation of ones' own volition. Respondents may have participated in order to obtain the vouchers without actually wanting to be a study participant or engage in qualitative interviews which involve speaking about personal issues (e.g., experiences with their LTC), which for some could cause distress. Particularly, this might be an issue for children from more economically deprived families, for whom the offer of vouchers could help them to afford items they may not be able to obtain otherwise. However, a literature review exploring the provision of financial incentives to young research participants concluded that compensation for the participants' time or an incentive to participate in the form of a gift token is appropriate and does not unduly influence young people to participate in studies against their own interests (377).

It is widely believed that financial incentive for participation in research is permissible when the risk of harm to the individual is negligible in terms of probability and degree of the harm occurring (378). The research outlined in this chapter was deemed low risk to participants. For this reason, the NHS Research Ethics Committee assessed the study as eligible for a proportionate review. A proportionate review provides an accelerated review of research studies that have minimal risk, burden or intrusion for research participants (379). In addition, participants were reminded of their right to choose not to engage in any activity or answer any questions asked in the interviews, as well as the right to withdraw at any time without providing a reason. Participants were informed that they would still receive the voucher should they chose to withdraw.

However, participants may not have felt comfortable withdrawing participation after already volunteering and commencing the interview, although consent should be an ongoing process. Although I had planned to ask participants if they wanted to skip a question or terminate the interview if I had noticed any signs of discomfort, I could have taken greater measures reinforce the notion of ongoing consent, reducing any

perceived barriers to withdrawing, such as expectation of confrontation. For example, Coyne and colleagues provided young participants LTCs (aged 7 to 16) with a "red card" which could be presented at any time and the interview would halt without question (380). Enabling participants to easily withdraw from the stay could help to build trust, which helps to develop rapport (363).

Generally, participants did not appear to find interviews distressing, although three participants spoke about dealing with mental health issues because of their conditions and had spoken. One participant touched on the topic of suicidal thoughts, but this was expressed as something she had experienced in the past as a result of her medication, for which she had sought help. She stated this was no longer an issue at the time of the interview. All participants were provided referral forms with contact information, including contact details for emotional support (ChildLine) (Appendix 3.19). However, if participants had indicated they were putting themselves at risk during the interviews, for example self-harm, suicide ideation, or non-adherence to healthcare regimens which could have serious implications to their health, I would have been ethically obliged to feed this information back to the gatekeepers, who were members of the participants' clinical teams responsible for identifying the participants. This had not been indicated on the information sheets nor consent forms, which described the confidential nature of the interviews and anonymity of data, nor had it been considered within the application to the Research Ethics Committee. In retrospect and in consideration of the well-being and safety of participants, details of what would happen should participants reveal they were at risk of serious harm should have been included in the ethics application, information sheets, and consent forms.

4.5.3 Findings in the context of other literature

The results from this chapter add to the growing evidence base identifying the significance of the relationship between the HCP and adolescent patient, and the importance of reducing the perceived power imbalance (381, 382). This is also a known barrier to SDM in adult populations in chronic care, and patients often undervalue the contribution of their personal knowledge to the decision-making, rather than that of HCPs' technical knowledge (256, 383). In paediatrics, the triadic relationship adds an additional complication, where parents can be perceived to block SDM. Parents can find it challenging to relinquish control over their child's LTC

for fear of poor health outcomes, and require clarification on their role from HCPs (260). HCPs commonly report parents' emotional state as a barrier to SDM (193). While adolescents value their parents' support in the decision-making process, they often prefer parents to have a lesser role. Adolescents with LTCs would like the chance to see HCPs alone to discuss sensitive matters, but are rarely offered this opportunity (204, 384). Parents worry about not receiving important information about their child's health, which they value over patient confidentiality (384). Discourse needs to take place between the three parties around adolescent confidentiality, which has the potential to empower and improve adolescent autonomy, and can allow them the opportunity to be forthcoming about potentially risky behaviours (384, 385).

Being invited to participate has been previously identified by adolescents as an important facilitator for SDM (193). HCP friendliness and direct communication are seen to be essential in adolescent healthcare delivery (138). HCPs also need to be mindful of other communication factors (e.g. tone of voice) when communicating with adolescents (138), as adolescents can fear judgement from HCPs, which has been previously reported to induce stress and affect disclosure (386).

Adolescents with LTCs sometimes lack confidence in their ability to be involved in the decision-making process and worry that they may not make the "right" decision. The concern of adolescents with LTCs around making a "wrong" healthcare decision has been reported before (227, 229). The SDM three-talk model emphasises in 'team talk' that the patient is informed that they are not left to make the decision on their own, the process is a partnership, and that patient's expertise and input in the decision-making process can be equally important as that of the HCPs (100).

4.5.4 Implications for practice

Adolescents spoke to me about the importance of feeling "normal" and do not want to feel as though they are set apart from others because of their LTC. Receiving a diagnosis of a LTC can change one's self-perception, triggering a multitude of emotions such as shock, anxiety, anger, fear, and despair (16, 387). It is important for HCPs to be aware of the language used when speaking to adolescents with LTCs, so they do not feel set apart from others. For example, Adam (aged 13) preferred to describe his malfunctioning organ as opposed to being referred to as a

diabetic. It may be useful to elicit suggestions from adolescents with LTCs regarding how they would like to refer to their condition. This is another way of providing adolescents with LTCs an element of control during discussions.

Adolescents recognise that their involvement preferences change, and it is vital that they feel they have control over this, as failure to meet involvement preferences can be detrimental to their well-being (204). In line with the core elements of SDM and patient-centred care, clinical strategies that elicit adolescents' context and perspective, provide support, and offer tailored guidance have been previously identified by adolescents as enabling their behaviour to change (388). Adolescents can vacillate between acceptance and avoidance of their condition, which affects the extent to which they engage during consultations. Adolescents with LTCs feel set apart from their peers socially and physically, but strive to live a normal life (330, 389). Having contact and support from other peers with a LTC is important in making adolescents feel normal, and peers can be seen as a resource to learn about LTC experiences and involvement (389). When SDM is seen as normative behaviour, it can encourage adolescents to be involved. Furthermore, SDM can allow for the selection of options which are most congruent with adolescents' values, preferences and sense of normality (99).

The tension adolescents with LTCs can experience between feeling that they "should" be involved in healthcare decision-making, but that HCPs and parents know the "best" option for them may make it difficult for adolescents to identify their role during consultations. Parents do not help this when they interrupt or answer for their child during discussions. HCPs could cultivate adolescents' understanding of the SDM processes, which emphasise the importance of patient expertise, and help adolescents to view SDM as a balance which is in line with their own values and beliefs. In addition, HCP training on how to foster parents to support their child's autonomy and involvement could be instrumental.

4.5.5 Implications for intervention development

The findings from this Chapter will be used to inform the development of an intervention to prepare and support the involvement of adolescents with LTCs in SDM, which will be discussed in depth in the next chapter (Chapter 5). In this chapter, adolescent participants emphasised the importance of being normal and

leading a normal life. The intervention should therefore take into account that this population does not want to feel differentiated from their peers. Elements which attempt to normalise issues around having an LTC and self-management, as well as being involved in the decision-making should be included. It should also be clear that SDM is encouraged by the members of their clinical team.

Adolescents with LTCs spoke to me about how the adults often have the control during consultations, and that they "know what's best". The intervention should seek to empower adolescents, perhaps by breaking down exactly how they can be involved in SDM. Also, by helping adolescents to become aware of their own expertise around their lives, values, and preferences so that adolescents are aware that their input in the decision-making is important in order to choose the best option for them. However, it is also crucial that adolescents with LTCs feel they have a say in their roles and the extent of their involvement in the decision-making, as well as in the decisions themselves, to emphasise optional as opposed to mandatory autonomy. The intervention should raise awareness that adolescents can and are entitled to see their HCPs alone. The intervention also needs to address the fact that parents are seen to hinder SDM from taking place with their child.

Participants talked about hesitance around being involved in discussions and decisions about their healthcare due to worries they might bother the HCP or say or ask something "stupid". The intervention needs to address fears and misconceptions around saying or doing something "wrong" while attempting to normalise this sensation.

4.5.6 Conclusion
The findings in this chapter are consistent with findings discussed in Chapter 2, including adolescents' experiences of power imbalance, and many times not being as involved as they would have liked. What this chapter adds is a more in-depth insight into perceptions of barriers and facilitators around SDM. These include self-efficacy; perceived outcomes of involvement; the extent they are provided the opportunity to be involved; readiness for SDM; and how SDM aligns with their developing identity and sense of normality. Although, as found in the systematic review (Chapter 2), preferences for involvement as indicated using the pie charts varied within and between participants, all participants wanted to be involved in

decision-making to some extent, often allocating the larger roles to themselves and HCPs in the ideal pie charts, preferring their parents to play a lesser, more supportive role in the decision-making process

These findings provide bases for the development of intervention components to target barriers and facilitators as perceived by the prospective users. From this, intervention objectives can be outlined along with key features (e.g., format, delivery, and content) of the intervention that can achieve the overall aims (preparing for and supporting SDM). Input from adolescents with LTCs into the intervention design enables these features to be informed by the users. The following chapter will discuss how Chapters 2 to 4 are used to inform the intervention development and design. As outlined in the previous chapter (Chapter 3) this is done using the Intervention Mapping Approach (201) to intervention development.

Chapter 5: Using the intervention mapping approach to design a booklet aimed to support and prepare adolescents with long-term conditions to be involved in shared decision-making

5.1 Chapter outline

This chapter aims to describe the development of an intervention to support and prepare adolescents with long-term conditions (LTCs) to participate in shared decision-making (SDM). Findings from the intervention design process, using the Intervention Mapping Approach (IMA) to facilitate selection of the format and content of the intervention based on the findings from Chapters 2 and 3, are reported. This chapter contributes to thesis Objective 4, resulting in an intervention prototype to be pre-tested (Chapter 6). Finally, the IMA will be critically evaluated for its usefulness as a framework for intervention development in the context of behaviour change for adolescents with LTCs.

5.2 Introduction

Complex behaviour change interventions need evidence regarding the effectiveness of individual components to understand how these interventions work. This is described as the intervention planning stage of the Person Based Approach to intervention development (200), which is described in Chapters 2 and 4 of this thesis. This chapter describes the second stage of the Person Based Approach (intervention design), which involves using themes arising from the previous stage (planning) to identify key issues, needs and challenges the intervention must address. The guiding principles created in this stage include key intervention design objectives and key features of the intervention needed to achieve said objectives. Intervention design objectives address the behavioural needs, issues or challenges that have been identified during the planning stage, and the components which address these barriers and/or facilitators are the intervention features (200).

As discussed In Chapter 1, the Medical Research Council (MRC) framework emphasises the importance of theories in intervention development for establishing the causal assumptions that underpin an intervention thus improving the potential for effectiveness (169). There currently exists an extensive body of literature around interventions aiming to improve healthcare SDM in adult health care (113) but there

have been only a handful of studies which report SDM interventions in paediatric care (115, 204, 208), many of which are aimed at the parents (114, 390, 391). In Chapter 3, several relevant theoretical models were evaluated in the context of SDM with adolescents with LTCs, and it was concluded that the IMA (201) would be more suitable than selecting a single theoretical model for intervention development. This method will guide the selection of suitable behaviour change theory or theories for developing the complex intervention for the area of interest. The IMA is a protocol for systematic theory and evidenced-based planning for behaviour change (201), which fulfils criteria recommended in the MRC framework, and provides a logical process for effective intervention decision-making, including how to integrate theory and evidence throughout the intervention development. As explained in Chapter 3, an advantage of the IMA is that it begins by mapping out the problem instead of starting with theory, which could lead to ignoring important factors that do not fit into a single existing theory, or hinder from addressing known problems in a new way (359). The IMA therefore ensures the intervention development is guided by the problem, as opposed to dismissing important factors by prematurely selecting theory.

5.2.1 Chapter aim and objectives

This chapter aims to describe the development of an intervention targeted at adolescents with LTCs to prepare and support them to be involved in SDM in accordance with the MRC framework and Person Based Approach. The chapter addresses three objectives: (a) to develop an intervention using the MRC framework, Person Based Approach and IMA; (b) to create intervention materials based on the results of the IMA development exercise; (c) to critically evaluate the IMA for its usefulness as a framework for intervention development in the context of SDM with adolescents with LTCs. Together, these chapter objectives will address thesis Objective 4.

5.3 Intervention Mapping Approach overview

The IMA is based on three over-arching perspectives: 1) a socio-ecological approach that recognised the importance of individual, social, and environmental factors as important determinants of health behaviours; 2) multi-theory and evidence-based; 3) stakeholder participation. The IMA includes six stages: 1) logic model of the problem, also referred to as the needs assessment; 2) programme outcomes and objectives

(logic model of change); 3) programme design (methods and strategies); 4) programme production (creating an organised programme plan); 5) programme implementation plan; 6) evaluation plan. This chapter will describe the intervention development stage of the MRC framework (169), which include Stages 1 to 4 of the IMA, and the first two stages of the Person Based Approach (planning and design) (200). Table 17 illustrates the IMA stages discussed in this chapter, and how they interconnect with those pertaining to the MRC framework (169) and Person Based Approach (200).

Table 17. Stages of the Intervention Mapping Approach (201) discussed in this chapter with coinciding stages of the MRC framework (169) and Person Based Approach (200).

MRC Framework (169)	Person Based Approach (200)	Intervention Mapping Approach (156)
Intervention Development: Identify the evidence base Identify/develop theory Modelling process and outcomes	Intervention Planning: identify key behavioural issues, needs and challenges	Stage 1 - Logic model of the problem (needs assessment)
	Intervention Design: Guiding Principles include intervention design objectives and intervention features.	Stage 2: Programme outcomes, performance objectives and determinants. (Logic model of change)
		Stage 3: Programme design (methods and strategies)
		Stage 4: Programme production (creating an organised programme plan)

5.3.1 Logic models

The IMA uses logic models in the different stages. These are graphic representations of the logical relationships between concepts, such as intervention components and outcomes (392). The logic models help intervention developers to take into account the complexity of health problems and possible solutions, demonstrating the pathways of programme effects, thus making a clear rationale for the intervention components (392). In the full IMA process, three types of logic models will be produced (201). In Stage 1, the first logic model will be presented, which is the logic model of the problem. This includes a description of the causes of the health problem, which in this thesis can be described as an absence of adolescent involvement in healthcare SDM. In Stage 2, a set of intervention models are produced which focus on the solution to the problem: logic model of change. This

model depicts the exact change that the intervention components will focus on, in respect to the target population, as well as the expected determinants of change. These models explain how the intervention components are thought to influence firstly the determinants of the behaviour, then the behaviour itself, and finally the health problem (lack of SDM). Finally, in Stages 3 to 4, a model of the intervention logic is completed and used to plan implementation (Stage 5) and evaluation (Stage 6), which will be discussed in Chapter 7 of this thesis.

5.3.2 Stage 1: Logic model of the problem (needs assessment)

Stage 1 involves assessing the problem, its related behavioural components and environmental conditions, and their associated determinants for the identified populations (201). This assessment involves developing an understanding of the targeted population (adolescents with LTCs), and their needs. The product of this stage is a description of the problem and potential behavioural and environmental causes and determinants of the behaviour. The first task is to assess what is already known about the target population, and what further information is needed (201). This includes developing an understanding of adolescents' attitudes and experiences around involvement in SDM, contributing to an overall logic model of SDM. With limited pre-existing literature regarding adolescents' perceptions of SDM (114), and minimal observed and reported instances of SDM with adolescents in practice (143), a systematic review was conducted to examine adolescents' attitudes and experiences with healthcare decision-making in general (Chapter 2) (204). Secondly, a qualitative study was conducted to address gaps from the systematic review, with a focus on adolescents' perceived barriers to, and facilitators of SDM (Chapter 4) (279). Figure 19 shows the thesis components of Stage 1.
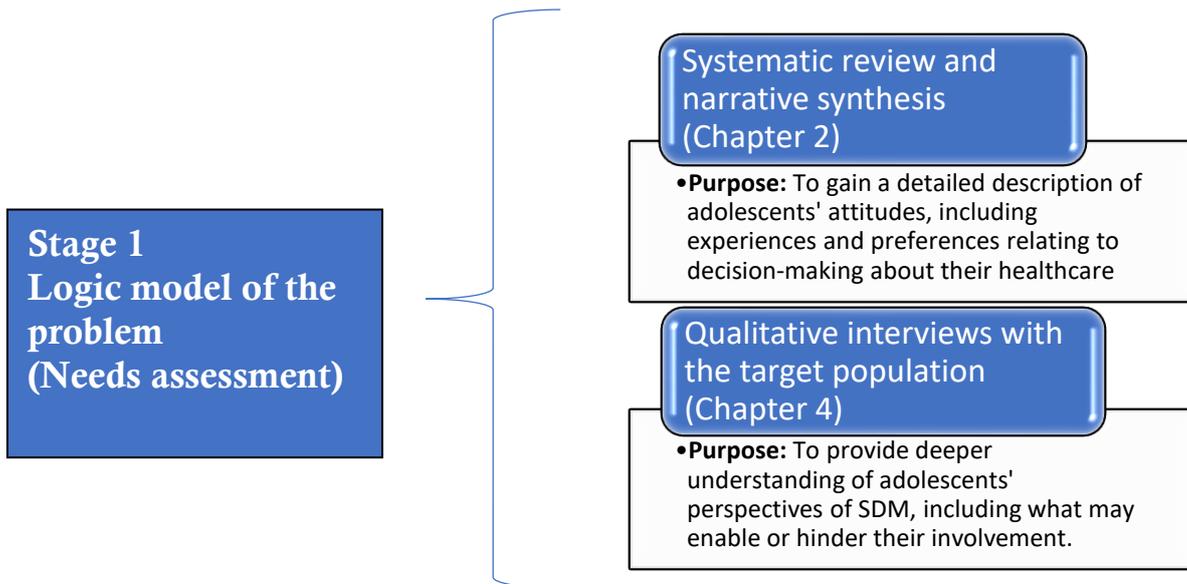
Figure 19. Thesis Components of the intervention mapping approach Stage 1

Bartholomew et al (201) recommend the use of a modified Predisposing, Reinforcing and Enabling Constructs in Educational Diagnosis and Evaluation (PRECEDE) model (393) to guide the logic model of the problem. In the PRECEDE model, health behaviour is regarded as being influenced by both individual and environmental factors, and the model is based on the premise that a diagnosis of a problem is essential before developing and implementing the intervention plan (393). Diagnosing the problem involves identifying a number of factors or determinants of behaviour. Personal determinants that can predispose the desired behaviour include knowledge, attitudes, beliefs, personal preferences, skills, and self-efficacy towards the desired behaviour (393). External factors can prevent or reinforce the desired behaviour, including social support and availability and accessibility of resources (393). Behavioural factors include the overt actions that can lead to the desired behaviour (393).

The logic model of the problem reads from left to right, however, formation of this logic model begins from right to left, starting with a description of the health problem (201). Next is the analysis of behavioural factors, which includes what the target population does that increases their risk of experiencing the health problem. The analysis of environmental factors includes conditions in the social and physical environment that can either influence the health problem directly or through the behavioural cause. For example, parents interrupting their son or daughter with an

LTC during clinical consultations could prevent the adolescent from asking questions resulting in not participating in SDM.

The next phase of the logic model of the problem is an analysis of personal determinants of behaviour and environmental factors. These determinants reside at the individual level, and are somewhat hypothetical as evidence for the determinants are usually correlational rather than causal (201). Finally, there are non-modifiable factors (adolescent characteristics such as age, gender and LTC) which still need to be considered in the needs assessment as they can influence the health problem as well as factors which are modifiable. For example, the length of time an adolescent has lived with an LTC could influence their involvement in SDM as well as self-efficacy around involvement.

As mentioned earlier, the health-related problem identified is the absence of involvement of adolescents with LTCs in SDM around their healthcare. This includes involvement in discussions with their HCPs around options and what is important to the patient, as well as the actual healthcare decision-making. As discussed in Chapter 1, evidence for the absence of involvement of adolescents with LTC in discussions and decision-making is strong (101, 102, 143), and SDM with this population is both recommended (55, 123) and likely beneficial to the patient (69, 114, 135, 394). So, working back from the health problem, the factors, or determinants of the problem (absence of SDM), which could also be described as barriers and facilitators, were identified for the target population (adolescents with LTCs) from mapping onto the logic model findings from Chapters 2 (systematic review) and 4 (qualitative interviews) (Figure 20). For example, external or environmental factors, including others' actions, could directly contribute to minimal involvement in SDM, or influence the adolescents' behaviours resulting in SDM not taking place. Behaviours could include failure to ask about options or voice values and preferences. Then personal determinants, such as adolescents' beliefs around their own expertise and abilities to make "good" decisions, were mapped onto the model. These determinants along with non-modifiable adolescent characteristics (e.g., age) contribute to the health problem, which can prevent the desirable behaviour from taking place, and when combined, form the logic model of the problem, or needs assessment (Figure 20).

Personal Determinants:
(adolescents with long-term conditions)

- Fearfulness/avoidance around certain information
- Not wanting to think about their condition
- Lack of motivation to be involved
- Lack of confidence around decision-making skills
- Fear of wasting the doctor's time
- Not wanting to be different from other adolescents
- Not wanting to think/talk about their condition
- Lack of confidence asking questions
- Afraid to say or ask something "stupid"
- Belief that the "adults'" contributions are more valid/important
- Lack of confidence in own knowledge and expertise
- Not being able to remember what they want to say/ask
- Feeling uncomfortable speaking with HCPs
- Viewing consultations as a negative experience
- Perceiving a lack of control over decisions and decision-making
- Not feeling ready to be involved
- Belief that they are not "allowed" to have a say
- Concern about making a "wrong" decision
- Fear of being reprimanded

Behavioural Factors

- Not asking HCPs questions
- Avoiding being involved in discussions
- Not always voice opinions including values and preferences around options
- Asking or allowing parents to speak on their behalf
- Relying on others to make the decisions
- Taking complete control of healthcare decisions

Health Problem (shared decision-making does not occur)

Adolescents not participating in SDM with HCPs

Environmental Factors

- HCPs sometimes don't provide adequate information about LTCs and available healthcare options
- Use of overly technical jargon
- Lack of time in appointments
- Parents interrupting/speaking for adolescents
- Presence of others in the room
- Power imbalance

Adolescent characteristics

- Acute physical and mental wellness
- Elapsed time since diagnosis
- Age
- Long-term condition

Figure 20. Logic model of the problem

5.3.3 Stage 2: Programme outcomes and performance objectives; logic model of change

In Stage 2, a logic model of change and matrices of change objectives are developed (201). These specify exactly what needs to change in the behaviour and environment in order to improve the health problem, and what needs to be achieved to reach the performance objectives that will change the behaviour or environmental conditions in order to reach the intervention goals. This stage provides the framework for the intervention, outlining pathways of the intervention effects. This differs from Stage 1, which involves pathways to identify causes of the problem. In Stage 2, the focus shifts from the problems to the solutions (change processes). Therefore, the logic model shifts from that of the problem, to one of change. To create this model, behavioural and environmental outcomes of the intervention are specified based on the evidence gathered in the needs assessment (Stage 1). Firstly, the desired health outcome is stated (participation in SDM), then behavioural outcomes are identified (from Stage 1), then the performance objectives (behavioural outcomes broken down into specified behaviours), and finally the change objectives and determinants (what determinants need to change and how).

5.3.3.1 Behavioural outcomes and performance objectives

Behavioural outcomes for the logic model of change can be derived from behaviours identified for the logic model of the problem in Stage 1. Performance objectives are a list of specific processes or actions in the form of statements of what the target intervention user will do, or how they will modify the environment. Identifying the performance objectives involves subdividing the behavioural outcomes. I used the essential SDM components, as derived by Makoul and Clayman's (99) systematic review and integrative model of SDM in medical encounters to assist in breaking down the behavioural outcomes in specified behaviours in order for SDM to be achieved

However, this model is aimed at clinicians and my intervention is to be aimed at patients. Therefore, only the patient-oriented components, where patients perform the action, were used as performance objectives (Table 18). These components were then matched with the three-talk model of shared decision-making (100) and any missing components were added to the performance objectives in line with the model (Figure 21).

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As outlined in Chapter 1, these models break down the SDM process into concrete behaviours, enabling specific performance objectives to be identified at this stage. Although the models were developed for use with adult patients, a literature review aiming to clarify SDM in the paediatric field outlined comparable concepts (131). These include reciprocal information exchange acknowledging all parties having their own unique expertise, where the evidence for the potential benefits and risks of healthcare options are discussed, acknowledging the young patients' preferences, as well as understanding their experiences, establishing the outcomes important to the patient and determining their preferences during the deliberation process, then progressing to decision-making (131). Both models have been used previously to inform the development of an intervention to facilitate SDM in adolescent mental health (271).

Table 18. Performance objectives based on patient-oriented essential components of SDM (99)

Makoul and Clayman's essential components of SDM	Patient- Oriented?
1: THE HEALTH ISSUE IS EXPLAINED:	No
2: THE POSSIBLE OPTIONS ARE PRESENTED :	Yes – Patients need to understand/ ask about options Patients need to actively listen to explanation of options
3. THE PROS AND CONS OF EACH OPTION ARE DISCUSSED:	Yes – Patients need to consider what is important to them and your lifestyles Patients need to communicate and deliberate values/preferences in line with options
4. DISCUSSION OF PATIENT SELF-EFFICACY:	Yes – Patients need to consider, evaluate and discuss how capable they feel of following through with healthcare option(s)
5. UNDERSTANDING IS CHECKED:	No
6. ARRANGE FOLLOW UP	No
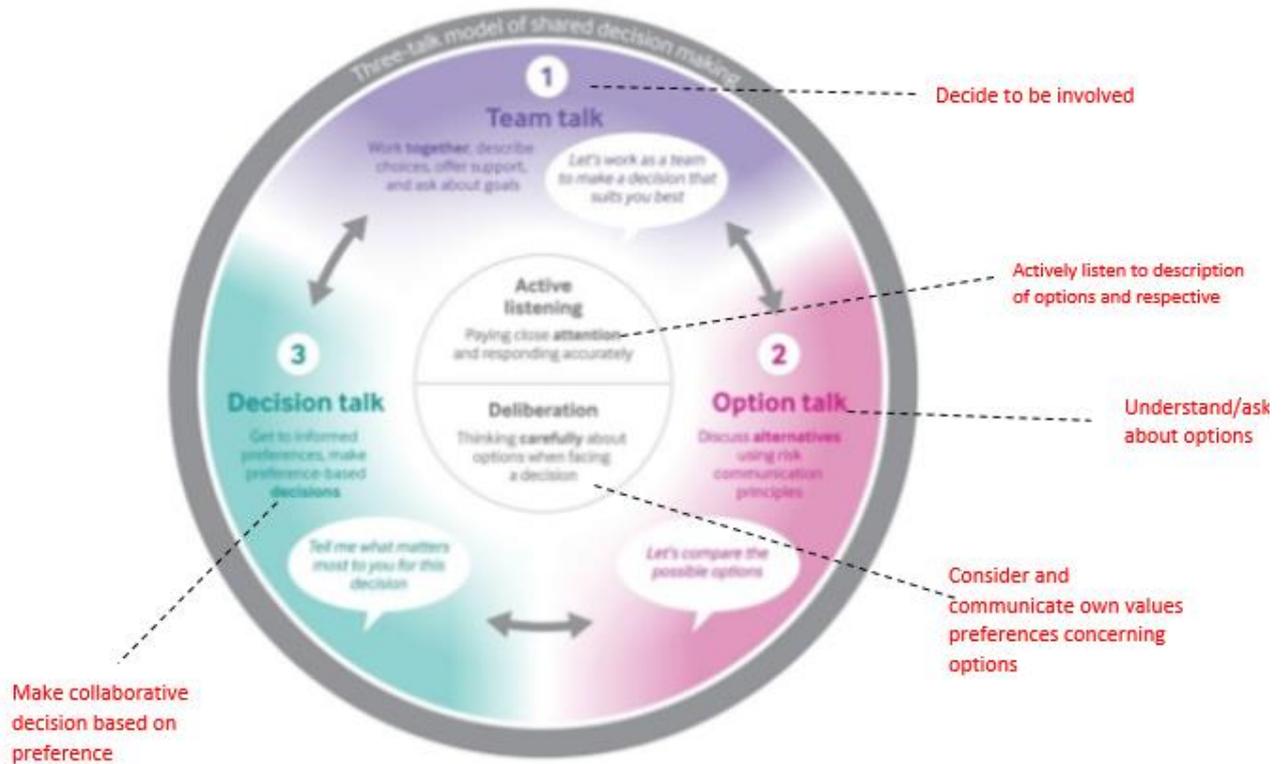
Figure 21. Performance objectives based on the three-talk model (100)

5.3.3.2 Change objectives and determinants of behaviour

In order to develop the logic model of change, the determinants of behaviour must be identified (201). At this point, appropriate behaviour or behaviour change theory can be selected which complements the findings from Stage 1 (needs assessment). To develop the list of determinants (factors that influence whether behaviours can be changed), theoretical constructs are selected from the literature, based on their importance for changing behaviours. A single unifying theory is not necessary; however, the nature of the behaviours and their determinants can suggest theory or theories. Selecting theory based on the targeted behaviours that are required to change in order to meet the intervention outcome ensures that developers are not restricted to following a single theoretical model. The IMA draws upon different theories for different purposes (201). This supports the argument that combining multiple theoretical approaches will add to a more complete understanding of the intervention (359). Several theoretical constructs were critically evaluated in Chapter 3 of this thesis, including the Health Belief Model (395), The Reasoned Action Approach (296) and Social Cognitive Theory (297), and it was concluded that the selection of theory would come after the gathering of evidence in Stage 1 (needs

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assessment) was completed, as recommended by the IMA (201). Many of the theoretical models outlined in Chapter 3 could not alone account for the determinants and factors described in the needs assessment, as they omit important concepts which have been identified in the needs assessment as affecting adolescents' involvement in SDM.

For example, the Health Belief Model (395), Reasoned Action Approach (296) and Social Cognitive Theory (297) do not account for emotion, which has been identified as a determinant for SDM involvement as some adolescents with LTCs express fearfulness around receiving certain information about their condition (204). The Health Action Process Approach (301) does not adequately consider the role of social norms in behaviour, which is particularly important for the target population who express a need to feel that their involvement is supported by parents and HCPs, and that participation in SDM is a normal for them to do (204, 279). Other theoretical models, including the Information–Motivation Behavioural Skills Model (299) and the Transtheoretical Model of Change (396), were rejected as they were not deemed appropriate for the health goal, or targeted behaviour change (299, 396). However, the Theoretical Domains Framework (TDF) (202, 291), which is a synthesis of 33 behaviour and behaviour change theories, includes 14 domains, such as emotion and social role (Table 19), could be applied to, and cover, the determinants outlined in the needs assessment. Therefore, given the range of factors influencing behaviours and environmental factors identified in Stage 1 of the IMA which were not included in other behaviour change theories, the Theoretical Domains Framework (TDF) was used to identify the determinants of change (202, 291). Although not all the TDF domains tie in with the needs assessment in Stage 1, the determinants (personal and environmental) from the logic model of the problem (Figure 20) were mapped onto the relevant TDF domains (202), which were then used to articulate the determinants of behaviour (Figure 22). Change objectives are the specific actions that would need to occur change to achieve the performance objectives and finally overall intervention goals.

Table 19. Domains of the Theoretical Domains Framework and definitions (202)

Domain	Definition
1. Knowledge	Awareness of the existence of something
2. Skills	Ability or proficiency acquired through practice
3. Social role and identity	A set of behaviours and displayed personal qualities of an individual in a social setting
4. Beliefs about capabilities	Acceptance of the truth, reality or validity about an ability, talent, or facility that a person can put to constructive use
5. Optimism	Confidence that things will happen for the best or that desired goals will be attained
6. Beliefs about Consequences	Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation
7. Reinforcement	Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus
8. Intentions	Conscious decision to perform a behaviour or a resolve to act in a certain way
9. Goals	Mental representations of outcomes or end states that an individual wants to achieve
10. Memory, attention and decision processes	Ability to retain information, focus selectively on aspects of the environment and choose between alternatives
11. Environmental context and resources	Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour
12. Social influences	Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours
13. Emotion	Reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event
14. Behavioural regulation	Anything aimed at managing or changing objectively observed or measured actions

Personal Determinants: (adolescents with LTCs)

- Fearfulness around certain information
- Viewing consultations as a negative experience
- Not wanting to think about their condition
- Lack of motivation to be involved
- Belief that the "adults'" contributions are more important
- Lack of confidence in own knowledge
- Lack of confidence asking questions
- Lack of confidence around decision-making skills
- Fear of making the "wrong" decision
- Perceiving a lack of control over decisions and decision-making
- Belief that the "adults'" contributions are more important
- Not wanting to be different from other adolescents
- Belief that they are not "allowed" to have a say
- Feeling uncomfortable speaking with HCPs
- Fear of wasting the doctor's time
- Not being able to remember what they want to say/ask

- Not feeling ready to be involved

- Not perceiving involvement as beneficial

- Lack of understanding around condition and treatment options including pros and cons.
- Lack of understanding how to be involved

TDF Domains

Emotion

Goals

Belief about Capabilities

Skills

Optimism

Social role & identity

Social Influences

Memory, attention & decision processes

Intentions

Beliefs about consequences

Knowledge

Environmental Factors:

- Healthcare practitioners sometimes don't provide adequate information about LTCs and available healthcare options
- Use of overly technical jargon
- Parents interrupting/speaking for adolescents
- Lack of time
- Presence of others in the room

Social influences

Environmental context & resources

Figure 22. Theoretical Domains (202) which map onto personal determinants and environmental factors to be used as determinants of behaviours.

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5.3.3.3 Logic model of change

As mentioned above, the logic model in Stage 2 is similar to the logic model of the problem (Stage 1), except it represents the pathways of intervention effects rather than pathways of problem causation. As in Stage 1, although this logic model reads from left to right, model production begins on the right and works backwards, starting with the health outcome goal to be achieved by the intervention (SDM). Working left from the outcome goal, the behavioural and environmental changes necessary to achieve the health outcome are stated. The next link in the model is the specification of performance objectives to achieve the behavioural or environmental outcomes. Finally change objectives specify what needs to change in the determinants of behavioural or environmental outcomes to accomplish the performance objectives (Figure 23)

5.3.3.4 Matrices of change

The performance objectives and the determinants of behaviour derived from the TDF domains (202) were used in the development of the matrices of change objectives (Table 20). The performance objectives (specific behaviours that should occur in order to achieve the desired outcomes) and the determinants of behaviours (factors that influence change) are outlined. Performance objectives are cross matched with determinants in the matrices of change, and change objectives are established. Change objectives state what the intervention components should modify to influence performance objectives to achieve the behavioural and environmental outcomes, ultimately reaching the health goal (SDM). So, the final output of Stage 2 is a set of matrices that combine performance objectives with personal determinants to produce change objectives, which describe what needs to change related to the determinant for the individual to achieve the performance objective (Table 20).

Personal determinants with change objectives:

Emotion: Relaying positive emotions towards receiving information about their condition and treatment options and being involved in SDM

Goals: Feeling motivation to be involved and goal-setting

Belief about capabilities: Feeling confident in their ability to ask questions and be involved in discussions and decisions

Skills: Having the skills to gather the necessary information and be involved in discussions and decision

Optimism: Expressing positivity around SDM involvement and outcomes

Social role and identity: Feeling that being involved in SDM is normal, and that others similar to them participate in SDM

Social Influences: Feeling that others approve of their involvement in SDM

Memory attention and decision processes: Able to remember information about their conditions and options, as well as the questions they want to ask

Intentions: Making the conscious decision to be involved in SDM

Beliefs about consequences: Expecting SDM to have a beneficial outcome

Knowledge: Understanding the pros and cons of the available options, as well as how to be involved in SDM

Performance objectives:

1 Decide to be involved in SDM

2. Ask about Options (What are they, what are the pros and cons of each)

3. Actively listen to description of options and respective pros/cons

4. Consider own vales preferences concerning healthcare options

5. Communicate values and preferences

6. Consider, evaluate and discuss capability of engaging in healthcare options

7. Make a collaborative decision based on preferences and option pros/cons

Behavioural outcomes:

• Adolescents ask HCPs questions
• Adolescents are involved in discussions
• Adolescents voice their opinions
• Adolescents do no ask or allow parents to speak on their behalf
• Adolescents are involved in healthcare decisions
• Adolescents make healthcare decisions with HCPs

Health outcome (SDM takes place)

Intervention Goal: Adolescents are supported and prepared to be involved in shared decision-making about their healthcare

Figure 23. Logic model of change

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Change objectives	Determinants											
	Personal										Environmental	
Performance Objective (Adolescents)	Cognitive and interpersonal skills	Emotion	Motivation and goals	Belief about capability	Social role and identity	Memory attention and decision processes	Social Influences	Intentions	Beliefs about consequences	Knowledge	Environmental context and resources	Social Influences
PO 1.0 Decide to be involved in SDM	CIS 1.0 Demonstrate the ability to be involved in SDM	E 1.0 Feel positive about being involved in SDM	M 1.0 Recognize benefits of SDM	BAC 1.0 Feel confident in being involved in SDM	SOI 1.0 Recognise that other adolescents are involved in SDM	MADP 1.0 Remember to be involved in SDM	SI 1.0 Feel that being involved in SDM is encouraged	I 1.0 Intend to be involved	BAC 1.0 Expect being involved in SDM will have a positive outcome.	K 1.0 Know how to be involved in SDM	**Barrier/ enabler: time. This barrier cannot be influenced by intervention but will be taken into consideration for implementation**	**Barrier/ enabler: support and encouragement of parents and HCPs. This will be taken into consideration in the development of the intervention targeted at adolescents**
PO 1.1 Ask about Options (What are they, what are the pros and cons of each)	CIS 1.1 Demonstrate the ability to ask questions	E 1.1 Feel positive about asking about options	M 1.1 Acknowledge benefits of asking	BAC 1.1 Feel confident asking questions	SOI 1.1 Recognise that other adolescents ask about options	MADP 1.1 Remember to ask questions	SI 1.1 Know when to ask questions and recognise it is encouraged	I 1.1 Intend to ask about options	BAC 1.1 Expect that the doctor will provide information about options	K 1.1 Know the questions that need to be asked		
PO 1.2 Actively listen to description of options and respective pros/cons	CIS 1.2 Demonstrate ability to actively listen	E 1.2 Feel positive about actively listening	M 1.2 Acknowledge the benefits of understanding about options	BAC 1.2 Feel confident in ability to pay attention and understand options		MASP 1.2 Remember to actively listen		I 1.2 Intend to actively listen to information about options	BAC 1.2 Expect that it will be beneficial to understand options			
PO 1.3 Consider own vales preferences concerning options	CIS 1.3 Demonstrate ability to match preferences to options	E 1.3 Feel positive about considering values/ preferences	M 1.3 Acknowledge the benefits of matching preferences to options	BAC 1.3 Feel confident in ability to identify values and preferences		MADP 1.3 Remember to consider vales/ preferences	SI 1.3 Recognise that HCPs encourage you to consider preferences	I 1.3 Intent to consider values and preferences	BAC 1.3 Expect that matching preferences to options will have the best outcome	K 1.3 Know pros and cons of the options in relation to preference		
PO 1.4 Communicate Values/preferences	CIS 1.4 Demonstrate ability to communicate options	E 1.4 Feel positive about communicating values /preferences	M 1.4 Acknowledge the benefits of communicating preferences	BAC 1.4 Feel confident in ability to voice values/ preferences	SOI 1.4 Recognise that other adolescents voice their preferences	MADP 1.4 Remember to communicate preferences	SI 1.4 Recognise that HCPs want you to communicate these	I 1.4 Intend to communicate preferences	BAC 1.4 Expect that preferences will be taken into considering			
PO 1.5 consider/evaluate/discuss capability of engaging in options	CIS 1.5 Demonstrate ability to evaluate and discuss capability	E 1.5 Feel positive about evaluating and discussing capability	M 1.5 Acknowledge the benefit of evaluating and discussing capability	BAC 1.5 Feel confident in ability to discuss capability	SOI 1.5 Recognise that other adolescents evaluate and discuss capability	MADP 1.5 Remember to discuss capability	SI 1.5 Recognise that HCPs want you to discuss capability	I 1.5 Intend to consider/evaluate/discuss capability	BAC 1.5 Believe that discussing capability will lead to the best decision	K 1.5 Know about own capability		
PO 1.6 Make collaborative decision based on preference	CIS 1.6 Demonstrate ability to be involved in a collaborative decision	E 1.6 Feel positive about being involved in a collaborative decision	M 1.6 Acknowledge the benefit of making a collaborative decision	BAC 1.6 Feel confident in ability to be involved in a collaborative decision	SOI 1.6 Recognise that other adolescents are involved in collaborative decisions	MADP 1.6 Remember to be involved in a collaborative decision	SI 1.6 Recognise that HCPs want you to be involved in a collaborative decision	I 1.6 Intend to make a collaborative decision	BAC 1.6 Expect that being involved in a collaborative decision will lead to the best outcome			

5.3.4 Stage 3: Programme design (selecting methods and strategies)

Stage 3 involves working from the logic model of change (Stage 2, Figure 23) and matrices of change (Stage 2, Table 20) to begin conceptualising and designing the intervention. The plan from this stage includes intervention themes, components, theory- and evidence-based methods and practical applications (201). Important emphasis is placed on methods for change, which is underpinned by theory, and practical applications for delivering the intervention. Considering intervention parameters is necessary for designing an intervention which is effective, and ensuring an adequate analysis of the intervention content (290). In Stage 3, theory-informed methods and practical strategies are chosen in attempt to change behaviour of the target population (201). The tasks in this stage include reviewing programme ideas, identifying and selecting theoretical methods, deciding on practical applications, and ensuring that the final chosen applications address the determinants and change objectives from the previous stages. Ideas are generated with involvement from stakeholders, then theoretical methods and practical applications are selected.

5.3.4.1 Change methods

A theory- and evidence-based change method is a technique for manipulating the determinants of behaviour and environmental conditions (201). To facilitate the selection of methods to address change objectives, Bartholomew et al (201) developed a comprehensive list of change methods, related theory, parameters for use, and practical examples in relation to determinants that are commonly found to result in behaviour change in health promotion publications (e.g. skills, knowledge, self-efficacy). These methods address how the behaviour change outlined in the matrix is achieved (e.g., adolescents with LTCs remember to ask questions about their options). Appropriate methods are selected to match the change objectives according to their determinants outlined in the behaviour change matrix. For example, 'control beliefs' based on the Reasoned Action Approach (296) could be used to address self-efficacy around SDM involvement. Practical applications refer to how the change methods are delivered in ways that fit the target population in the context of the intervention (201). For example, one of the change objectives is to increase adolescents' self-efficacy to ask questions about healthcare options. For the change objective of increasing self-efficacy, theoretical methods might include

modelling or skill training. One application for modelling would be providing stories of other adolescents with LTCs, outlining how they were involved in SDM in the first person. Selecting theoretical methods before practical applications ensures these are guided by theory, instead of being selected because they are attractive to the audience (397). However, from the content analysis in Chapter 4, ideas, and suggestions from adolescents with LTCs can contribute to the process.

So, to get from the matrices with changes objectives from Stage 2 to the selection of methods in Stage 3, the methods are matched to the determinants. To ease this process, I was able to translate the determinants of behaviour based on the TDF(202) from Stage 2 to Bartholomew et al's (201) determinants grouped according to categories of theoretical methods (Table 21) without losing any key concepts. This enabled Bartholomew and colleague's (201) comprehensive list of theory-based methods and parameters to be utilised in the intervention design. Each determinant often has multiple suggested change methods, along with objectives to be influenced by each method (201). For example, modelling could be effective in improving skills-related change objectives but may need to be paired with a self-monitoring behaviour to ensure that the modelling has been interpreted successfully by the user. The importance of context is emphasised by ensuring the parameters for effectiveness are considered in the translation from methods to practical applications. Such parameters for effectiveness are the specific conditions under which the behaviour change methods are effective (201). For example arguments can be a useful method of changing attitudes, but only if the argument is new to the target population (201). The consideration of parameters in the IMA aligns methods for change that are underpinned by theory with the practical applications for delivering the intervention (290).

In selecting the methods for change, the first step was to apply the basic methods, and then methods geared to change certain determinants. As the intervention to meet the thesis aims is targeted at the individual level, basic methods at the individual level should be considered. Bartholomew and colleagues (201) list the basic requirements of health education and promotion at the individual level. Although other levels of the socio-ecological model are taken into consideration in developing this intervention (e.g., interpersonal), the intervention described in is mainly aimed at the individual level (adolescents with LTCs). Additional levels of the

socio-ecological model (e.g., HCPs and LTC clinic administration) will be taken into consideration in implementation, discussed in Chapter 7. Table 22 illustrates how the intervention aims to meet the basic requirements. The relevant categories of theoretical methods from related theory (Table 21) and parameters to select and develop examples for inclusion in the intervention (201) are shown in Table 23.

Table 21. Determinants Based on the TDF (202) translated to Bartholomew et al's (201) determinants grouped according to categories of theoretical methods.

Determinants Based on TDF (202)	Determinants grouped according to categories of theoretical methods (201)
• **Knowledge**	• Knowledge
• **Motivation and goals** • **Belief about consequences** • **Emotion (optimism)**	• Attitude, belief, outcome expectations
• **Social role & identity** • **Social Influences**	• Social Influence
• **Memory attention and decision processes** • **Belief about capability** • **Cognitive and interpersonal skills** • **Physical Capability**	• Skills, capability, and self-efficacy and to overcome barriers
• **Intentions**	• Habitual, automatic, and impulsive behaviours

Table 22. Basic Methods at the individual level of the IMA (201)

Basic Methods at the individual level		
Methods	**Parameters**	**Applications**
Participation	Requires willingness by the health promoter to accept the participants as having a high influence; requires the participants; group to possess appropriate motivation and skills.	Adolescents were involved in the development of the booklet draft and will be providing feedback for the final version.
Belief Selection	Requires investigation of the current attitudinal, normative and efficacy beliefs of the individual before choosing the beliefs on which to intervene.	The booklet seeks to change several beliefs that act as barriers to SDM. These beliefs were explored in the qualitative interviews. Examples include that they will say or ask something stupid or make the wrong decision, that HCPs know better and do not want them to be involved.
Persuasive communication	Messages need to be relevant and not too discrepant from the beliefs of the individual; can be stimulated by surprise and repetition. Will include arguments.	This will be done using repetition, facts, and quotations from other adolescents.
Active learning	Time, information, and skills.	Users will select factors important to them, and complete a table listing pros and cons of available option. Users are encouraged to write down questions to ask HCPs
Tailoring	Tailoring variables or factors related to behaviour change or relevance.	Users complete tick activity with factors important to them, and a table based on their own options. Users are reminded that their level of involvement is their choice.
Individualisation	Personal communication that suites learner's needs	Users are reminded to ask their healthcare team if they have any additional questions or concerns.
Modelling	Attention, remembrance, self-efficacy and skills, reinforcement of model, identification with model. Coping model instead of mastery model	Stories of adolescents with LTCs in which they successfully were involved in SDM. These are real stories and include personal difficulties which have been overcome.
Facilitation	Requires real changes in the environment, identification of barriers and facilitators, power for making changes and usually intervention at a higher environmental level to facilitate conditions on a lower level.	Having a physical booklet form to bring into an appointment may prompt HCPs to facilitate SDM, for example to provide options and descriptions of risks/benefits to fill in the booklet.

Table 23. Methods to change with parameters and applications (201)

Determinants and Change Objectives	Methods	Parameters	Applications
Methods to increase knowledge	Provide cues	These work best when people can select cues.	Prompts cue the stages of shared decision-making and factors relevant to the individual can be selected and completed Prompts to ask clinicians if users have any queries, and questions can be selected Language like "you can…." offers options and choice to the user.
	Instruction on how to perform behaviour		Step by step explanation of what SDM is and how it is performed
Methods to change attitude, belief, outcome expectations	Environmental-Re-evaluation	Stimulating cognitive and affective appraisal to improve appraisal and empathy skills	Stories and images show adolescents as an involved patient, and their HCPs are described as encouraging involvement. This is represented through images and repeating key messages in a range of formats, including quotations. Key questions and concerns (e.g., "What if I make the wrong decision?") are addressed
	Arguments	Arguments need to be new to the message receiver	Potentially novel SDM-related facts introduced
	Repeated Exposure	Neutrality of the original attitude	Repeated quotations from actual adolescents promoting SDM involvement. Images of involved individuals
Methods to change social Influence	Information about others' approval	Positive expectations are available in the environment	Explaining that HCPs want them to be involved. Encouragement to bring the booklet to the consultation. Explaining that adolescents with LTCs can choose who is in the room. A section for parents to help them support adolescents' participation
	Provide opportunities for social comparison	Use comparison to help setting goals.	Real stories of other adolescents with long-term conditions and how being involved in SDM has benefited them Images of a range of adolescents, including different ethnicities, to relate different demographics.
Methods to change Skills and self-efficacy	Verbal Persuasion	Credible Source	Adolescents with LTCs are informed by HCPs that they are also experts Adolescents with LTCs are encouraged to evaluate their confidence to engage in selected option
	Self-monitoring behaviour	Monitoring must be of specific behaviour	Adolescents with LTCs are prompted to record comments, questions etc.

5.3.5 Stage 4: Programme production

Stages 1 to 3 inform the work to be completed in Stage 4. In Stage 4, messages and materials are produced which bring the initial intervention themes and ideas that were generated in Stage 3 to life. As intervention components are designed, context and setting(s) must be considered. It is recommended to involve potential users in the intervention design (201). Adolescents identify themselves as having different needs to children and adults, and prefer their care to be adapted as such (164, 248). Therefore, it is important to develop an intervention based on the view of the user, addressing their accounts and preferences. The SDM three-talk model (100) is built on the premise that patients are experts in the decision-making process, they have important knowledge and understanding of their needs and therefore their input is key to the development of an intervention for them. Furthermore, the effectiveness of educational/health care resources can be more relevant to the target population if patients' insights into the management of their condition are incorporated (166). Adolescents with LTCs have demonstrated the ability to contribute to the development of interventions aimed at encouraging involvement during consultations, thus increasing the potential for intervention acceptability for this population (164). Stage 4 focuses on establishing the main elements of the intervention and producing intervention components and materials as a prototype to pre-test with potential users before making plans for implementation and evaluation. This pre-testing will be described in the following chapter (Chapter 6).

To facilitate the process of programme production, consultation with stakeholders is required to establish their design preferences. This was done during the qualitative interviews with adolescents with LTCs (Chapter 4). The last section of the interviews included questions which focused on format, delivery, design, and content of the intervention. Adolescent participants were asked about ideas for an intervention, and this part of the interviews underwent a content analysis. The results of the content analysis will be used to inform intervention production. Suggested interventions included a mobile application, poster, and booklet, with booklet being the most commonly suggested medium. Advantages and disadvantages of a booklet were therefore considered (Table 24), and it was decided that the initial intervention production would begin with this format, with the potential for future adaptation.

Table 24.Consideration of booklet for intervention channel (201)

Channel/vehicle	Typical uses, methods, and practical applications	Advantages	Disadvantages
Display Print: Brochure	Skill Training Modelling Information with extensive detail Persuasion Vicarious Reinforcement	-Can affect a variety of learning and change objectives -Focused on a single issue or build as part of multi-strategy messages -Use for community-based learning and entry to households -Used to reinforce messages and deliver key messages -Lend to Multilanguage formatting	No standard distribution routes exist as they do for circulating print Use for specific project Depends on reading literacy
RESPONSE to disadvantages:			Ideas for distribution point can be established in intervention prototype pre-testing (Chapter 6). The booklet can encourage information gathering from clinical team members, so that the content does not need to be condition specific As suggested by users, booklet will not be text heavy and reading level will be aimed below target age

Data from the interview participants' perspectives regarding acceptable content, intervention design, and the type of language that would most resonate with the target population were all important factors contributing to the production of the booklet intervention. For example, with regard to making the visual aspect of the intervention attractive to the target population, the adolescents with LTCs stressed that it should contain vibrant colours with images and diagrams. They felt it should be informal and not text heavy, using bullet points and non-technical language (Chapter 4). In order to ensure that language and booklet content were appropriate, direct quotations from the adolescents with LTCs who participated in the qualitative interviews were included, and stories of their experiences participating in decision-making were used to provide real examples as they had recommended.

At the programme production stage, I attempted to ensure that the design of the booklet would be appealing to the target audience by making the design age

appropriate. I worked with a graphic designer who specialises in producing fun, creative, and contemporary visual communications (Jessica Draws Media Ltd). Meetings with the designer (JD) took place to incorporate the findings from the content analysis (Chapter 4) to feedback into the design of the intervention. Adolescent-appropriateness in health materials is important in engaging young people and delivering quality healthcare (69, 138). Therefore, phrasing and quotations derived from the language used in the qualitative interviews (Chapter 4) were included as much as possible. A small stakeholder group of adolescent advisers who had experience with consultations with HCPs but did not have a disclosed LTC provided feedback on the booklet throughout the development process to ensure the language, content and design would be acceptable and accessible to an adolescent audience. This group included two males and two females aged 16 and 17 who were personally known to me. JD provided a selection of designs images to represent the booklet content. During the discussions with the stakeholder group, adolescents commented on the language, images, colours, and design. The group discussed and decided on the best options provided, and gave further feedback on how content and designs could be improved. For example, it was felt the colouring could be more vibrant throughout the booklet to draw attention. In addition, suggestions for changes to the characters' clothing were made so they would be more representative of what adolescents today would wear. It was also suggested that the participants could be more culturally diverse. The adolescents in the stakeholder group were sent the final drafted prototype via e-mail after all suggested changes had been made for it to be signed off for their approval.

Feedback for booklet drafts was also received through discussions at my supervisory meetings, which include SDM experts and one general practitioner who were members of the PhD supervisory team (FW, NJW and AE). Suggestions were made concerning the language used to ensure that key SDM concepts, such as patient-centredness, were effectively portrayed, and to provide insight to acceptability within a clinical context. All supervisors also signed off on the final drafted prototype.

The various intervention components incorporating theory-based methods were established, contributing to the final planned intervention prototype titled "*It's my body, I can have a say*" booklet (Appendix 5). This title quotation was extracted from the interviews conducted in Chapter 4. When asked to why his preferred role for

involvement was larger than what he experienced, 14-year-old Rhys recruited from a rheumatology clinic explained: *"I suppose if decisions are being made for you it's it's not, you should have some like most involvement in the decision, about what medication, because It's my body, I can have a say."*

Table 25 provides further details about each component of the intervention with page numbers.

Table 25. Detailed outline of the "It's my body, I can have a say" booklet development

Section	Key Messages	Determinants	Theoretical methods	Practical Application
Page 2: Why should I read this booklet?	· There are many adolescents living with LTCs, so they are not alone or differentiated · HCPs want adolescents with LTCs to be involved in decision-making about their health · Patient contribution to decision-making is important · Being involved benefits patients	• Attitude, belief, outcome expectations •Social Influence •Skills, capability, and self-efficacy and to overcome barriers	-Information about others' approval -Arguments -Verbal Persuasion	This page includes colourful bullet points containing important information about SDM. Key words are highlighted for impact.
Page 3 - 5: How to become more involved	· Adolescents with LTCs can be involved in SDM by asking questions about their options. · Understanding the available options and considering patients' values around their options is crucial for SDM.	•Knowledge •Skills, capability, and self-efficacy and to overcome barriers	-Provide cues -Guided practice -Self-monitoring -Instruction how to perform the behaviour	Page 3 includes an infographic for users to follow and provides questions prompts that users can ask HCPs. Users are directed to page 5 to input answers and page 11 to record any further questions or comments. On page 4, users are provided common examples of key values and preferences relating to healthcare options which they can select or include their own. On page 5 users are encouraged to record information gathered relating to options, including benefits and risks and select what they feel to be the most appropriate option. Then they are asked to rate how comfortable they feel about undertaking the chosen option (self-efficacy).
Pages 6-7: Questions and concerns	· HCPs will support patients in the selection of the best decision for you · Patients are welcome to see the doctors alone · What patients ask or say is not "stupid"	• Attitude, belief, outcome expectations •Social Influence	-Environmental-Re-evaluation -Information about others' approval	Page 6-7 provide answers to common questions and concerns raised by adolescents with LTCs.
Pages 9-9: Patient Stories	· Other adolescents with LTCs are, and are able to be involved in SDM · SDM has had a positive outcome for other adolescents with LTCs	•Social Influence •Skills, capability, and self-efficacy and to overcome barriers • Attitude, belief, outcome expectations	-opportunities for social comparison -Modelling/ demonstrating behaviour -Environmental-Re-evaluation	Page 8 includes three stories of adolescents with a range of LTCs who speak of their experiences of being involved in SDM.
Page 10 – Parent's Section	· Parents can see the benefits of their child's involvement · Parents can support and encourage involvement	Social Influence	-Information about others' approval	Page 9 includes a section which users can chose to give to their parent which explains why SDM is important for their child, and that they can support their child to be more involved.
Page 11: Space to write questions or comments	· The questions and concerns that adolescents with LTCs have are important and should be addressed.	•Skills, capability, and self-efficacy and to overcome barriers	-Self-monitoring behaviour	Page 11 provides a space to write down questions or comments to prompt users and help them remember to use them during consultations

5.4 Discussion

This chapter describes the developmental process of the *"It's my body, I can have a say"* booklet which is guided by theory and informed by users using the IMA. The development of the intervention was informed by a body of evidence which suggests that the intervention needs to motivate patients, encourage, and support involvement, promote information exchange, normalise participation, and provide reassurance and confidence. To my knowledge, it is the first intervention developed to promote SDM for adolescents with LTCs. Research on improving SDM in clinical encounters with young people so far lacks a tradition in systematic intervention development (115, 206, 208, 398). This chapter provides an example of how the systematic development of a theory- and evidence-based intervention programme is possible using the IMA. The IMA was a useful tool to structure the planning of the intervention, integrating insights from different experts, theories, empirical studies, and target group members. Furthermore, the transparent description of the development of the intervention may be helpful for the design and evaluation of future interventions.

Applying each of the first four different stages of the IMA provided useful insights, which then guided the subsequent stages. As part of the needs assessment (Stage 1 of the IMA) a systematic review of existing evidence (Chapter 2), supplemented by qualitative interviews to fill in any knowledge gaps (Chapter 4), enabled the selection of an appropriate theoretical framework (TDF (202)) from which relevant domains were used to create the matrices of change objectives (IMA Stage 2, Table 20). Designing and producing the final programme prototype (Stage 4) partly overlapped with selecting methods and strategies (Stage 3). Factors that could influence the adoption and implementation of the booklet will be explored in the prototype pre-testing for evaluation in the following chapter (Chapter 6). Although the IMA Stages 5 (programme implementation plan) and 6 (evaluation plan) did not fit within the remit of the PhD project, a proposed design for implementation and evaluation of the booklet is discussed in Chapter 7.

It should be noted that although the IMA takes a socio-ecological approach, this intervention is aimed at the individual level. The justification for this is to create a product which is guided entirely by the adolescent voice, which is particularly important for this population as their voice is often underrepresented in healthcare

encounters (143, 261). At an individual level, the booklet is not able to address all the possible determinants of the desired health outcome, as certain organisational factors (e.g., time to ask questions) or interpersonal factors (e.g., parental and HCPs' active encouragement of SDM) are not a focal point. This is not to say that other levels have been disregarded; they are indeed crucial to supporting the involvement of adolescents with LTCs in SDM. For this reason, the booklet has been designed with a section for parents, and adolescents are encouraged to bring the booklet into the consultation in hopes that this will prompt HCPs to involve adolescents in SDM. However, the booklet would ideally not act as a stand-alone intervention and will be delivered in conjunction with HCP training. This could include training for SDM delivery, communication with adolescents with LTCs and managing parents, which was recommended in Chapter 4. This will be explored in the proposal for an implementation plan, discussed in chapter 7.

5.4.1 Strengths and limitations

A potential drawback of the IMA process is that it could be used as a "cook book" with little flexibility (397). The sample of methods used to address change objectives provided are based on frequency of published health promotion programmes, and is by no means exhaustive (201). A balance is required between using the framework to guide this process, while maintaining an iterative and interactive approach to developing an intervention.

Bartholomew and colleagues (201) emphasise the importance of stakeholder involvement in intervention, but provide little guidance on how to involve stakeholders in decisions, and little clarity for how much weight should be given to their responses in addition to evidence, theory, and researcher judgements. Authors of IMA papers often omit details about how stakeholders contribute, so little can be learned from previous research in this field. Adolescent stakeholders were integral to the development of the intervention described in this thesis, which was a key strength of this research as the target users are valued for providing a greater breadth of skills, knowledge, and expertise beyond a solely expert-driven approach (201). I was able to use the interviews in Chapter 4 to not only explore perceived barriers and facilitators around SDM, but also to generate ideas around intervention format, design, and content.

However, involving adolescent stakeholders is not without its challenges. One of the key findings from the interviews with adolescents with LTCs is that they often do not like to think or talk about their condition. This could be an explanation for the difficulty with recruitment, with a low response rate described in Chapter 4 (279). With a hard-to-reach population, and the time restrictions of the PhD, organisation of a regular stakeholder group would have been logistically challenging. For this reason, I approached a group of adolescents who were personally known to me. However, these adolescents did not have any disclosed LTCs, so their feedback on the booklet content may not have been relevant to the target audience. It could have been useful to include adolescents with LTCs at this stage, which would have strengthened the co-production element of the intervention. For example, it might have been more appropriate to go back to the participants involved in the initial qualitative interviews (Chapter 4) to gain their perspectives about the intervention components drafted as a result from their suggestions, and whether/how the prototype met their expectations. In addition, in designing a page for parents, it would have been useful to have parents' insights regarding the acceptability of this section. However, the intervention was designed to be targeted at adolescents with LTCs, with the parents' section as an addition for adolescents to pass on as they chose.

Despite these issues, the adolescent advisers were able to provide an age-appropriate perspective, such as providing insight into the booklet design including the appearance of the young characters. Continuous feedback contributed by these volunteers influenced the key decisions around research methods and intervention development. Finally, further pre-testing by stakeholders, including adolescents with LTCs and HCPs who work with this population is described in the next chapter (Chapter 6), resulting in amendments to improve the booklet usefulness and appropriateness with the target audience. Further plans for evaluation of the intervention acceptability and feasibility of implementation will be discussed in Chapter 7.

In developing the "*It's my body, I can have a say"* booklet, Makoul and Clayman's integrative model of SDM (99) and Elwyn and colleague's (100) three-talk model of SDM were used to identify specific performance objectives (e.g. communicate values and preferences) to cross reference with determinants (e.g. beliefs about capability) in order to determine the change objectives to be met by the intervention

components for the intervention goal (i.e. SDM) to be achieved. However, these models were developed for SDM with adult patients and have been criticised for their use in paediatrics for conceptualising SDM within the context of the physician-patient dyad with no reference to other involved parties (i.e. parents) (399). The Elwyn et al (100) three talk et al model specifically has been criticised for its use in paediatric healthcare as it assumes a binary relationship between patient and HCP when paediatric consultations nearly always involve at least one parent or guardian (132).

Krockow and colleagues (399) recently conducted a review to understand health decision-making with children and adolescents with LTCs resulting in recommendations for extending Elwyn et al's three-talk model (100). The adapted version of the three talk model emphasised the importance of HCPs' support at the different SDM steps specifically with younger patients, including drawing awareness of the decisions being based on patient preferences; checking existing knowledge relevant to their condition using age-appropriate terminology and avoiding overwhelming with overly detailed information; encouraging patients to contrast short-term benefits of unhealthy behaviours with long-term benefits of resisting said behaviours; and establishing peer support networks of informed adolescents with similar conditions (399). Although this extended three-talk model adapted for use with adolescents with LTCs includes concrete suggestions on the doctor's approach to involving patients, the stages of the model and adolescent patient behavioural outcomes or performance objectives as outlined in Table 20 (e.g., ask about options and consider and communicate values and preferences) remain seemingly the same. However, it is also recommended that the complexities within adolescent and parent relationship be considered in depth as they could cause complications when attempting to work through the SDM stages and children mature, they are more likely to form different health opinions from their parents (399). This is beyond the scope of this PhD thesis, but should be considered in the implementation plan for pilot testing and process evaluation of the intervention for which a proposed protocol is discussed in Chapter 7.

Selecting a theory to establish the determinants to underpin the intervention was challenging. The determinants did not map on to a single behaviour change theory that had been discussed in Chapter 3. Furthermore, the target behaviour (SDM participation) is complex, and not a health behaviour that is heavily theorised in

comparison with other health behaviours (e.g., engagement with physical activity or smoking cessation). However, the IMA was used in to overcome this challenge. This framework has been widely used for mapping the factors that influence behaviour change as part of intervention development, and has been used previously in the context of the IMA for developing interventions aimed at young people (400, 401). As the TDF is a synthesis of numerous behaviour and behaviour change theories, using this framework meant that theory-based determinants were relevant to the evidence determined by the needs assessment.

5.4.2 Conclusions

This chapter describes in detail the theoretical basis, intervention techniques and strategies of a booklet which aims to improve the involvement of adolescents with LTCs in shared decision-making by using the IMA. The development of an intervention using the IMA is complex and time consuming but provides a comprehensive framework for effective decision-making at each stage in intervention planning and design. The next chapter (Chapter 6) describes the pre-testing process, whereby the prototype booklet was tested with focus groups of adolescents with LTCs, and HCPs who could potentially integrate the booklet into their clinical pathways.

Chapter 6: Pre-testing of the *"It's my body, I can have a say"* booklet using the think-aloud technique

6.1 Chapter Overview

This chapter presents the results of pre-testing of a prototype of an intervention which aims to prepare and support adolescents with long term conditions (LTCs) to participate in shared decision-making (SDM). The intervention is in the form of a booklet titled: "*It's my body, I can have a say*". This Chapter addresses thesis Objective 5 outlined in Chapter 1 (Page 21). Findings from focus groups of adolescents with LTCs and healthcare professionals (HCPs) who could integrate the booklet into their clinical pathways will be reported. Changes to the intervention for further evaluation, and suggestions for implementation will be outlined. Implications and recommendations for the intervention in the future will be explored.

6.2 Introduction

The development stage of the Medical Research Council (MRC) guidance for complex intervention development (402), as discussed in Chapter 1, consists of three tasks: identifying the evidence base (Chapters 2 and 4), identifying/developing appropriate theory (Chapters 3 and 5) and modelling process and outcomes, which will be discussed in this chapter. The modelling process involves delineating the intervention components and examining how they may relate to outcomes prior to a full-scale evaluation. This enables refinements to be made to the intervention design and provides important information about the design of both the intervention and the evaluation to come. The modelling process ties in with the development and evaluation stage of the Person Based Approach (347), and the last task of Stage 4 (programme production) of the Intervention Mapping Approach (IMA). Following development of an intervention prototype (Chapter 5), the next task is to pre-test the intervention components (201). Pre-testing is a key component of intervention development, as once the intervention prototype has been created, further qualitative research is essential to gain insight into whether the intervention is acceptable, interesting, persuasive, easy to use, and feasible to deliver (200).

Bartholomew et al (201) describe pre-testing as a process of trying out the specific intervention components, including key phrases and visuals proposed to portray the main ideas, with the intended users before the final production (201). This process is

important as it can provide an understanding of the potential users' interpretation of the intervention, as well as the discovery of words, phrases and vernacular they use when discussing the topic (201). Pre-testing is also critical in order to determine whether the planning up until this stage has resulted in the production of an intervention that has potential to achieve the desired outcomes. The pre-testing phase can provide reassurance that the assumptions made during the intervention development to date are correct, or identifies whether changes are needed to address these assumptions.

In addition, feedback from individuals who may be involved in intervention delivery will enable assessment as to whether and how the intervention could fit with current practice (implementation). Pre-testing precedes pilot testing, which consists of trialling the intervention as it will be implemented, with implementers (e.g. HCPs) and intended participants (i.e. adolescents with LTCs) to inform a much larger scale randomised control trial (RCT) (201, 403). A protocol for pilot testing of the intervention will be proposed in the next chapter (Chapter 7). The Person Based Approach (200) recommends the think-aloud technique as a pre-testing evaluation method as it involves eliciting and observing participants' immediate reactions to every element of the intervention, enabling the researcher to also observe how it is used, and then iteratively modify the intervention to optimise acceptability and feasibility (404).

6.2.1 Chapter aims and objectives

The aim of this chapter was to conduct a pre-testing of the intervention prototype agreed in Chapter 5 in the form of a booklet titled "*It's my body, I can have a say*". Specifically, the objectives were to: (a) assess the reactions and impressions of adolescents with LTCs and HCPs regarding the booklet content, design, readability, usability, and potential implementation and (b) use the findings to propose changes to future versions of the intervention for further evaluation.

6.3 Methods

6.3.1 Recruitment and data collection

Pre-testing was conducted with two key groups: focus groups of adolescents with LTCs and individual interviews and one focus group with HCPs who provide care for adolescents with LTCs. For the ease of describing the methods and results these

groups will be referred to as the users and HCPs. All participants were offered the opportunity to review transcripts of their data and make amendments if they felt their views had not been accurately represented.

6.3.1.1 Think-aloud method

The think-aloud method was originally used in cognitive interviewing to help develop and test survey questions. It enables researchers to gain insight into how participants interpret and answer the survey questions to validate the questions and inform the design and improvement of surveys (405, 406).

The think-aloud method involves participants speaking aloud any words which come to mind while they complete a task, which can provide a detailed picture of participants' feelings and thought processes (203). Think-aloud research methods have been found to be effective in providing a valid source of data about participant thinking, particularly during language-based activities, such as reading (203). These methods have been increasingly used to understand and make explicit HCPs' clinical reasoning processes, such as diagnoses and decision-making, so that others are able to learn from these processes (407-409). The think-aloud technique was found to be effective in evaluating user acceptability of interventions aimed at improving health behaviour in adolescents (410, 411). The process has been found to enable the collection of individuals' authentic and unfiltered first thoughts and impressions about the intervention (203). Think-aloud was there for determined as an appropriate method for meeting the chapter objectives, which include assessing the booklet acceptability of the in amongst those who are meant to use it, including how it can be improved.

I began the interviews and focus groups by reading standardised instructions and I demonstrated thinking aloud by completing a similar task. User participants were then asked to read through each item of the intervention, complete the tasks, and prompted to voice their opinion of each item as they went along. This was followed by discussion questions which explored factors relating to the intervention acceptability and implementation. The questions addressed general views including overall impressions, what was liked/disliked, and ideas for improvement and implementation.

6.3.1.2 User focus groups

A key finding in Chapter 4 was the importance of social norms around SDM involvement. Adolescents with LTCs do not want to feel differentiated from their peers. Focus groups are ideal for collecting data of current normative behaviour within a specific social group (412). Focus groups are also optimal for intervention pre-testing as they facilitate the collection of data on group norms, narratives and language (412).

When conducting a focus group, Bloor and Wood (412) suggest that rather than the question-answer format of a typical semi-structured interview, the facilitator should seek to generate a discussion within the group on the specified topic, which can be achieved by asking the group to perform a set task. The task set for the user group was to read and complete the sections of the booklet and engage in the think-aloud method while completing the process. Intra-group discussion around the task completion process enables the norms within that group around the intervention to emerge (412). Kitzinger (413) recommends conducting sessions in a relaxed fashion, with minimal interruption from the facilitator initially, then later encouraging debate and discussion around inconsistencies. Therefore, after providing instructions and modelling the think-aloud technique, I allowed the users to begin without intervening, and then later encouraged discussion by asking questions like "*Interesting, why's that?*" or "*could you tell me a bit more about that?*"

Kitzinger (413) argues that groups of individuals that already work, know one another, and work together are useful for focus group researchers as they may be able to tap into data that approximates to naturally occurring social interactions. Users were recruited from pre-existing groups of adolescents with LTCs who participate in meet-up events, such as football matches and filmmaking, facilitated by NHS youth workers who attend the hospital secondary care clinics, or in collaboration with local charities (e.g., *Valley & Vale Community Arts*). As observed in Chapter 4, the youth workers and organised events were only present and available for those attending the renal and endocrinology paediatric and transition (young adult) clinics, so users were only recruited from these groups for the intervention pre-testing. As I aimed to conduct focus groups with participants who were already acquainted, I was unable to recruit a focus group of adolescents with neurological or rheumatological conditions. Furthermore, early in the process it was

determined that recruiting individuals to a focus group would be too challenging within the allocated time frame.

Bloor and Wood (412) argue that while different groups may contrast one another, within each individual group participants should be relatively homogenous, as it can minimise power imbalances and increases the likelihood of shared understandings. The members of each focus group had similar LTCs (i.e., either renal or endocrinological) and were of similar ages (either 12 to15 or 16 to19).

Eligible adolescents were identified by members of the endocrinology and renal teams who organised and referred the secondary care clinic attendees to the meet-up events. Potential participants and parents were provided information sheets about the study prior to the previously arranged meet-up event, and informed that they could participate immediately after the event took place if interested. Participants provided consent/assent, and consent from parents of participants aged 12 to 15 was also obtained.

A purposive sample was attempted to have an even split of males/females and ages 12 to 15 and 16 to 19. Other similar qualitative studies which aimed to evaluate the acceptability of health interventions targeted at adolescents reached saturation with around 10 participants (164, 410). Therefore, I aimed to recruit a minimum of 10 adolescent participants for the pre-testing. The inclusion and exclusion criteria for adolescent participants were the same as the qualitative studies described in Chapter 4; eligible participants had to have been living with a long-term condition for at least a year. The participant age range was stipulated as 12 to 19 years.

The first group was given the full booklet to read through and complete the activities while thinking aloud. However, I noted that this activity was not as interactive as anticipated, as the participants worked through the booklet at different speeds, which made discussion difficult. Following reflection and discussion with my supervisory team, in the subsequent sessions I distributed sections of the booklet one at a time for users to complete and/or read though and think-aloud and discuss. For example, I distributed each of the points on Page 2 (Figure 24) individually and asked the participants to read, think-aloud and discuss whether they thought the point was true or false (all the points were true). After the think-aloud task had been completed for all sections of the booklet, I distributed the booklet as a whole before eliciting

comments regarding overall impressions and the design. As with the interviews outlined in Chapter 4, adolescent participants received £20 Amazon vouchers as a token of appreciation.

Why should I read this booklet?

Around **30% of young people** are affected by one or more long-term health conditions like eczema, asthma, epilepsy, diabetes, arthritis and many more.

In most of these cases, there will be choices of how **YOU can manage YOUR condition.**

When different healthcare choices are available, your doctors and nurses want you to be involved in these decisions, which affect **YOU and YOUR** life, and will support your involvement.

Doctors and nurses are experts on health conditions and treatments, but **YOU are the expert on YOU and YOUR life.**

Teenagers with long-term conditions say that the benefits of being involved in decisions with doctors include: feeling more positive and confident, less worried, and more satisfied with the decision.

Being involved in discussions and decisions with your doctor or nurse means you can find the best treatment/healthcare plan that really suits YOU and YOUR lifestyle.

Figure 24. Booklet Page 2 - points cut up and distributed individually

6.3.1.3 HCP participants

The aim was to recruit a sample of ten HCPs to match the user sample. E-mails were sent to contacts who had assisted with recruitment for the qualitative interviews presented in Chapter 4, and they were asked to circulate the correspondence among their teams. These included paediatric renal, epilepsy and endocrinology and rheumatology clinic teams at regional hospitals. Individual interviews were selected as the data collection method for the HCPs for several reasons; firstly, unlike the user group, I was not looking to explore the group norms, narratives, and everyday language of the HCPs. I was primarily interested in gaining insight into their impressions of the usefulness of the booklet within their teams, and how the booklet could be integrated into the current clinical pathways. Secondly, although I still employed the think-aloud technique in the interviews, I did not set the task of

completing the booklet sections as I did with the intended users. Instead, I had specific questions for the HCP group according to the study aims, which took the form of a semi-structured interview (Table 26). Thirdly, hierarchies exist within clinical teams, making it very difficult to recruit a homogeneous group as recommended (412). Finally, with complex and demanding schedules of the HCPs, arranging a convenient time and place to conduct a focus group session was considered to be relatively unfeasible. Therefore, I set out to conduct individual interviews, in most cases in HCPs' place of work. However, the paediatric endocrinology team stated a preference for a focus group session to be conducted during their monthly meeting, so one focus group was included.

Table 26. Interview schedule for healthcare professionals

A. OVERALL PURPOSE OF THE MATERIALS		
	Sample Question	***Follow up***
1.	What were your first impressions of the booklet?	*Positive / negative / neutral?*
2.	What did you think the main purpose of the booklet was?	*Do you think that this would be obvious to patients?*
3.	What would you say were the key messages for you?	
4.	In what way do you think that the booklet would help [your] patients/team?	*What are the advantages/disadvantages of them using the booklet?*
5.	What do you think about the booklet title?	
6.	How do you think the booklet could be used within your team?	*When do you see the materials being given to patients?*
7.	How could you integrate the booklet into existing clinical pathways?	*How easy do you think this would be?*
B. FORMAT & DESIGN		
8.	What do you think about the overall design of the booklet?	*Colour scheme, text size/font, Length, size?*
9.	What do you think about the illustrations and character design?	
10.	How easy do you think your patients would find it to use and understand the booklet?	*Is the information clearly presented?*
11.	What other ways could we present this information to patients?	*Different formats e.g. phone apps, website?*
C. SPECIFIC ELEMENTS		
12.	What parts of the booklet did you particularly like/dislike?	*Why?*
13.	What would you add/take away?	
14.	Do you have any other suggestions for improvement?	

6.3.2 Data analysis

I analysed the transcripts of the interview and focus group sessions using the framework approach (414). The framework approach enables the identification of commonalities and differences in qualitative data in order to draw descriptive and/or explanatory conclusions using a seven-stage guide (414) (Figure 25). This approach was selected due to the use of the Theoretical Domains Framework (TDF) (202) in the intervention development, with plans to map codes across the relevant theoretical domains during the analysis. Using the TDF as a basis for the framework approach could therefore provide insight into the participants' perceptions of the change methods, which were derived from the change objectives based on the TDF (Chapter 5). Furthermore, this study included both user (adolescents with LTCs) and HCP participants. The framework matrices of themes are developed to organise the data with summaries of each theme by participant or focus group, enabling the ease of comparison across groups. This could make it easier to identify any substantial differences between the HCPs and adolescents across the themes.
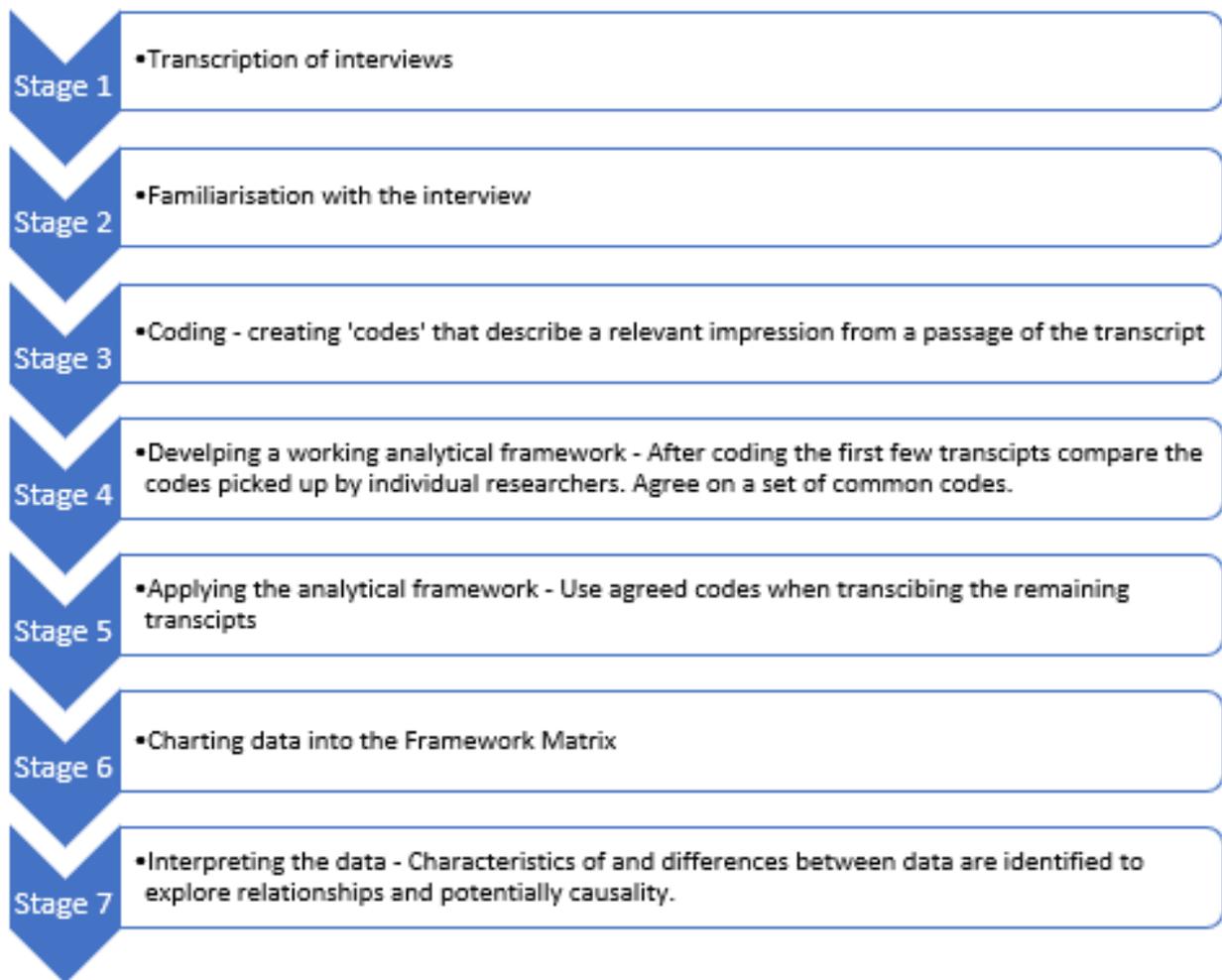
Figure 25. Seven stages of the Framework Method (414)

I transcribed the recorded sessions verbatim and became familiarised with data by reading and re-reading transcripts while listening to the audio recordings and recording initial thoughts and impressions. Transcripts were then uploaded to NVivo 11 (223) for coding. I then read through the transcripts line by line, applying codes to the relevant data. This began as an inductive approach referred to as "open coding" (414), with plans to later map the codes onto the relevant domains of the TDF (202) which had been utilised in planning and developing the booklet, as discussed in Chapter 5.

The reason for open coding instead of coding to the TDF domains was to reduce rigidity of being limited to the domains resulting in key ideas being overlooked if they do not fit with the framework. This inductive approach to framework analysis is similar to Braun and Clarke's (225) six-step thematic analysis in the beginning, but differentiates in the development of a framework which is then utilised in the coding

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of subsequent transcripts. Furthermore, the six-step thematic analysis does not rely on any theoretical underpinnings (225).

Gale and colleagues provide step-by-step guidance to develop and report the framework, including the use of independent coders (414). A Cardiff University third year medical student (KC), for whom I assisted with supervision, double coded all the transcripts, and wrote up the analysis as an assignment for her Self-Selected Component research experience course module. KC's contributed to the analysis only in this thesis, as her write up was separate to mine. KC became familiarised with the audio recordings and transcripts and coded the data separately. After coding the first four transcripts (two from the HCP group and two from the user group) we compared the assigned codes, discussed grouping common codes, and decided on a coding scheme for subsequent transcripts. Any new codes which did not fit into the initial framework were noted. Further discussions were held after coding four more transcripts and the initial framework was revised by adding and removing or merging redundant codes. At this point we revisited the decision to group the codes into the 14 TDF domains (202), and it was decided that this would be an overly granular representation of the data. Instead, the COM-B model was used, which condenses the TDF domains into three core components: capability, opportunity and motivation (348). Table 27 shows the TDF mapped onto the COM-B components. This became our analytical framework, which was applied to the subsequent transcripts using the agreed upon codes. After this, no new codes were identified, which suggests inductive saturation of themes (366). All transcripts were then revisited, and the final framework was then applied to each transcript. A map demonstrating the development of the analytical framework has been included in Appendix 6.

The data were then charted onto the framework matrix, which summarises the data by theme for each transcript: each matrix comprised one row per participant (HCPs) or focus group (adolescents). Along with summaries, illustrative quotations were included for each cell of the matrices (Appendix 7). This enabled organisation of the data for the write up, and eased comparisons between groups. The data were interpreted by reviewing the matrices and identifying characteristics and differences between the charts and exploring relationships within and between participants and themes. By charting the data, patterns in the data can be recognised including contradictory data, outliers or empty cells (414).

Table 27. Categorization of the COM-B model (348) and Theoretical Domains Framework (202)

COM-B components	Theoretical Domains Framework
Physical capability physical skill	• Physical skills
Psychological capability The capacity to engage in the necessary thought processes - comprehension, reasoning	• Knowledge • Cognitive and interpersonal skills • Memory, attention and decision processes • Behavioural regulation
Reflective motivation Beliefs about what is good and bad, conscious intentions, decisions and plans	• Professional/social role and identity • Beliefs about capabilities • Optimism • Beliefs about consequences • Intentions • Goals
Automatic motivation Emotional responses, desires, impulses and habits resulting from associative learning and physiological states	• Reinforcement • Emotion
Physical opportunity Opportunity afforded by the environment	• Environmental context and resources
Social opportunity Opportunity afforded by the cultural milieu that dictates the way that we think about things	• Social influences

6.3.3 Ethical considerations

Ethical approval was obtained from the NHS Research Ethics Committee and Cardiff and Vale University Health Board Research and Development Office (IRAS 232192, REC 17/LO/1694). Initially, I had proposed to conduct individual interviews with the adolescent group. However, due to the reasons mentioned above, it was later decided that focus groups would be conducted instead, so an amendment was submitted to the original application. While the qualitative interviews which are described in Chapter 4 focused on personal experiences, this qualitative study aimed to explore user impressions and reactions. Therefore, although complete confidentiality is not possible in a focus group, the discussion topic was not deemed to be overly sensitive. However, adolescents were reminded that the information shared within the sessions should not be repeated outside of the group. They were also informed both in writing and orally prior to the session that they could leave the focus group at any time or refrain from answering any questions. This appeared clear to the participants as one focus group member (Evan) requested to leave the session before the end, stating he felt tired. A group facilitator or parent was on hand in another room so that those who wanted to leave the group would not be left unattended.

6.4 Results

6.4.1 Participants

Four user focus group sessions took place with a total of nine female and five male participants aged 13 to 19 (mean= 16). Due to a small number of adolescents expressing interest in participating, a purposive sample was not achieved, resulting in more of a convenience sample. Three groups were recruited from meet-up events for adolescents with endocrine conditions: two groups consisting of three members and one group of two; and one group was recruited from an event for adolescents with renal conditions, which was a group of six. The elapsed time since diagnosis ranged from 1.5 to 10 years (mean = 4.7 years). The adolescent focus group sessions lasted between 45 and 57 minutes (mean=51 minutes). Details of the individual adolescent participants with pseudonyms are shown in Table 28 with an overall participant summary in Table 29. A total of 13 HCPs participated, with one focus group (six participants) and seven individual interviews. The HCP participants included five specialist nurses, four consultants, two psychologists, one dietician and one transition worker (Table 29). The HCP sessions lasted between 12 and 53 minutes (mean = 38 minutes). The HCP interviewed in the 12-minute session (Renal specialist nurse1) had to leave promptly to see a patient, so the interview was incomplete.

Table 28. Adolescent participants

Focus Group #	Participant	Gender	LTC Group	Age	Time Since Diagnosis
1	Rob	Male	Endocrine	15	4 years
1	Leah	Female	Endocrine	14	2 years
2	Liz	Female	Endocrine	14	2 years
2	Jade	Female	Endocrine	13	1.5 years
2	Evan	Male	Endocrine	13	3 years
3	Ashley	Female	Endocrine	19	8 years
3	Carys	Female	Endocrine	17	5 years
3	Dai	Male	Endocrine	17	10 years
4	Zoe	Female	Renal	16	3 years
4	Owen	Male	Renal	17	5 years
4	Eleri	Female	Renal	16	2.5 years
4	Lowri	Female	Renal	16	5 years
4	Dylan	Male	Renal	16	8 years
4	Seren	Female	Renal	17	7 years

Table 29. Participants summary

Adolescent participants		Health Care Professional Participants	
Total participants	N=14	Total participants	N=13
Gender		Gender	
Male	N=5 (46%)	Male	N=3 (23%)
Female	N=9 (64%)	Female	N=10 (77%)
Long-term condition of participant		Profession	
Endocrine	N=8 (57%)	Specialist Nurse	N=5 (38%)
Renal	N=6 (43%)	Consultant	N=4 (31%)
Age		Clinical Psychologist	N=2 (15%)
12-15 years	N=5 (46%)	Dietician	N=1 (8%)
16-19 years	N=9 (64%)	Transition worker	N=1 (8%)
Mean age	15.7 years	Specialisation	
		Nephrology	3 (23%)
		Neurology	1 (8%)
		Endocrinology	8 (61%)
		Rheumatology	1 (8%)

6.4.2 Overall impressions

Overall, both adolescents and HCPs reacted positively towards the booklet. They liked the design and layout and described it as a useful tool to facilitate and encourage adolescent involvement. All participants liked the title and front page of the booklet. However, every participant also pointed out aspects of the booklet that they did not particularly like and/or made suggestions for improvements. These included minor design and wording changes, noted typos, and amendments to the content. All but one adolescent (Ashley) said that they would read the booklet if given to them, and most stated that the secondary care clinic waiting rooms would be the best positioning of the intervention. HCPs agreed that the booklet would be ideally positioned in the clinic waiting rooms, and many said it would be useful for adolescents to bring it into the consultations.

6.4.3 Framework analysis

After coding four transcripts (two user group, two HCP group) the initial analysis consisted of 20 codes. After coding two additional transcripts, the codes were merged due to similarities in coded content, and then grouped into the three COM-B model categories (capability, opportunity, motivation). For example, codes for *individual/personalised* and *relevant* were grouped together as the theme '*Personally relevant and bespoke"* which was allocated to the 'motivation' category. Appendix 6 shows development of the analytical framework including the clustering of codes and categories. The final analytical framework that was applied to all transcripts consisted of seven themes clustered across three categories.

Data were then summarised into a matrix for each theme in the analytical framework, with one row per focus group (users) or participant (HCPs) and one column per theme. Quotations were extracted and entered into the corresponding cell (Appendix 7). These findings are described in greater detail below using the COM-B model as an organisational framework (348).

Although user and HCP transcripts were analysed together, they have been separated within each theme for comparison.

6.4.3.1 Capability

Adolescents described their ability to engage in SDM through having sufficient self-confidence, the necessary knowledge, and the tools to aid them in this process. In the analytical framework, two themes were developed in line with adolescents' capability relating to the booklet.

6.4.3.1.1 Knowledge and awareness of how to be involved and where to begin

Adolescents

When completing the 'weighing the options up' section on Page 5 of the booklet (Figure 26), some adolescents, particularly those under 16 years, said that they were not aware of their healthcare options. As Evan (aged 13) stated: "*I don't know my options, they just tell me*". Many adolescents said they found the process of completing Pages 3 to 5 (Figure 26) of the booklet helpful, although Leah (aged 14) admitted that she did not understand the term "self-management" at the top of Page 4. The booklet was described by adolescents as a useful tool which provides guidance on how condition- and option-specific knowledge can be gained from members of the adolescents' clinical team.

Figure 26. Page 3 to 5 of the 'It's my body, I can have a say' booklet

"*You know this where it's like 'start by asking' (Page 3). Like sometimes you just don't know where to start or what to say so you don't really ask them* [HCPs], *just like sometimes you can kind of find it hard to ask them those questions, but like maybe if the doctors or nurses um are telling you that you have more than one option, yeah I think that would help a lot*" (Owen, aged 17).

Adolescents also said that the booklet helped them to understand how they can be involved and that it eases the decision-making process by breaking it down and initiating reflection around options and preferences.

"*I like um like quizzes kind of the yes/no thingie to follow* [Page 3]. *And it helps you to know what to say, or like what you should know, like the risks benefits thingie* [Page 5]. *I've like never asked that question, and I think sometimes they don't say all the risks*" (Lowri, aged 16).

Zoe (aged 16): *I think it's good, I think it's like clear what you have to do, like it makes it clear, sort of breaks it all down to make it easier, yeah, I would use this*
Eleri (aged 16): *Yeah, it would to help like evaluate it, the decisions. If they give it to you with like a pen*
Dylan (aged 16): *Yeah, I would fill it in, yeah definitely like with the pros and cons*
Zoe: *Yeah, I think it's good to be able to see your pros and cons because it's, you know, it just makes it so much easier to decide, like if you have it before you go in to see your doctor, and then if you ask like so if there were bits missing to fill in, but it kind of, you know might, like get you to ask about them more to like, you know, help you fill it in and learn more*

HCPs

HCPs also said that the booklet helped simplify the process of how to be involved in SDM by preparing and enabling adolescents with LTCs to gain information about their condition and treatment options.

"Yes, I think it's quite a good little sort of flow chart of how to decide what, what they're going to do um, if they have a condition and they don't understand then they know that they need to ask questions. But if you get to the bottom and you found out they have a condition, they know what to do about it, they know the risks, then yes, they're ready to be involved in the decisions. This nicely breaks down the process, it just helps them to follow through and to think about the stages of it a little bit more than just "yes, I've got a condition, and they'll tell me what to do" (Rheumatology specialist nurse).

One HCP commented that the process of adolescents learning how to be involved in SDM by utilising the booklet could facilitate further understanding of their LTC.

"I think anything that's going to get people, um you know potentially more engaged with understanding their condition, you know be really on board with um, I can see it definitely being something that's useful" (Renal specialist nurse).

6.4.3.1.2 Having the confidence in skills, expertise, and ability to be involved.

Adolescents

Most adolescents said they had experienced some or all of the concerns described on Pages 6 and 7 of the booklet (Figure 27), particularly about asking or saying something "stupid" or making the "wrong" decision and said that the responses, such as "nothing you say is stupid" and "doctors and nurses <u>want</u> you to be fully informed" were encouraging. Adolescents noted that the booklet could help improve confidence around being involved in decision-making by drawing attention to adolescents' expertise around their own lives, and the importance of their contribution to the decision-making process.

"I think they [HCPs] can tell you as much as you want but only you know if you, you're gonna be ok with it or if you're gonna want it. I mean they are the experts on everything about health conditions, but not really about you because every person's different, so that's good" (Liz, aged 14).

Adolescents also commented that the booklet could help increase self-efficacy around asking questions. They expressed appreciation for the space to write down questions, which they said could help them to remember and feel less self-conscious about what they wanted to ask or say. As two adolescents discussed, the booklet

effectively addressed the common hesitance around asking questions they felt were obvious or that they should already know.

Carys (aged 17): *Um yeah sometimes if you ask something and maybe it's obvious what the answer is, it might feel a bit stupid asking it. Like if you've had it for years you should know*
Dai (aged 17): *Yeah, if it's important to you then no, it's not really stupid. If you wanna ask something you should, because if not you don't know it, like it says* [Page 7]. *And if you just go later and use like search like Wikipedia maybe it's not true so it's good to ask. And if you say 'nothing you say is stupid' maybe it can give people, like the patients the um the confidence and self-esteem so they don't feel so nervous to ask.*

Adolescents also stated that completing Pages 4 and 5 (Figure 26) of the booklet could increase skills and confidence in their ability to make a "good" decision.

"*I feel like the way that the options thing to fill it, with the list of what is most important to me, I feel like people, people don't often do that. It's hard to mentally weigh up the pros and cons. Once it's written down, I feel like uh it would help people a lot more to make a um a good decision, the right decision for them*" (Ashley).

HCPs

HCPs mentioned that the confidence scale on Page 5 of the booklet would be useful for adolescents to clinicians to gauge adolescents' self-efficacy around following a proposed healthcare plan. In addition, one HCP noted that it would be useful to suggest re-evaluating the options if the adolescent scored their level of confidence as low.

"*I like the confidence scale on there to help them rate themselves, I think that's useful for them and useful for us to see where they're at, and perhaps re-evaluate it's it's not quite high enough*" (Endocrinology specialist nurse).

"*Yes, this confidence rating* [Page 5] *is good, and actually quite useful for us clinicians to know. On this where it says: 'not confident at all' and 'very confident', if they're down in this side can you say: 'if you're not confident at all, you need to discuss this again'. Could be something like: if 5 or lower, maybe revisit your options. Because of course there's no point in choosing an option that you don't think you can do, or that they don't, yes, they don't feel confident about. Because they don't want to feel that they're being pushed into options*" (Rheumatology specialist nurse).

A specialist nurse described how the booklet could help provide adolescents with the necessary skills to be involved, where HCPs sometimes fall short.

"*so it's a bit of information about how they can actually start to go through with these processes which is really good because again, you know, if we don't equip them with*

the kind of skills and the certain things to ask and it's got clear examples here are some of the questions they can ask, that's really good, I think people will feel a bit more confident knowing the things to go in and say, they're probably more likely to actually ask the healthcare professional" (Neurology specialist nurse).

Here are some questions and concerns that **teenagers brought up...**

I don't always like to think or talk about my condition

I'm worried I'm going to ask or say something stupid

What if I make the wrong decision?

Your input is important, but you don't have to make any decisions on your own. Doctors and nurses won't suggest options that are "wrong" for you. Many decisions can be changed at your next appointment.

Sometimes I can't be bothered discussing things with the doctor or nurse

You don't always HAVE to be involved, but it can be helpful. Remember, doctors and nurses WANT to help you to have the best healthcare or treatment for you. Being involved can achieve that.

Thinking or talking about a health condition that affects you can be stressful. You can be in control of how little or how much you want to know. This may change over time and that's okay.

It's quite common to think this, in fact almost everyone does at some point. Think about it this way; if you don't ask, you won't know, and your doctors and nurses WANT you to be fully informed about your condition and your healthcare or treatment. Also, nothing you say is stupid.

What if my mum/ dad wants to be involved in the decision as well?

The last page of this booklet has been designed for you to give to your parents to read, if you like. You can ask to speak to the doctor or nurse alone for whatever reason, if you want.

"WHAT YOU THINK MATTERS, AND DOCTORS ARE THERE TO SUPPORT YOU"

"IF YOU TELL DOCTORS WHAT YOU THINK THEN THEY'LL TAKE THAT INTO CONSIDERATION, THEN IT BEST SUITS THE DECISIONS BECAUSE THEY ARE SUITED TO YOU"

You may have more questions or concerns, feel free to bring them up with a member of your healthcare team. There is space for you to write these at the back of this booklet.

Figure 27. Questions and concerns - Pages 6 and 7

6.4.3.2 Opportunity

Participants spoke about opportunity afforded by interpersonal influences and social norms in connection with the booklet. Two themes were identified in relation to opportunity, which were perceived reassurance and support, and shared experiences and social norms.

6.4.3.2.1 Perceived reassurance and support

Adolescents

Some adolescents said that at times they worry about bothering HCPs by voicing concerns. The booklet was described as encouraging and supportive. Adolescents frequently stated that the booklet provided reassurance that their involvement would be supported by others. For example, as several adolescents noted, the booklet makes it clear that HCPs want adolescents to be involved.

"It's got good questions and answers in it, like the ones we saw, um it's encouraging like shows the benefits of talking to the doctor and asking questions about your

decisions and that they um the doctors and um nurses that they want you to be involved, so it makes you feel good about speaking up your mind" (Liz, aged 14).

"I think like you read this and it makes you feel like, um like it's more, I don't know, not good, but normal I guess to ask those questions and stuff. Because sometimes you don't want to bother the doctor or ask a daft question, but here it says you should, and they want you to" (Rob, aged 15).

However, Ashley (aged 19) pointed out that the booklet failed to clarify whether the answers to the questions and concerns (Page 7) came from actual clinicians, and expressed that this should be made explicit in order for the information to be trusted:

"with this though if maybe just a bit at the bottom that says where the information comes from, like if there is a um like a reliable source like a doctor or nurse or something, then um something at the bottom that obviously says that like if you believe the information are from doctors and nurses themselves so if there's a little bit written that they sort of answered the question it becomes more sort of realistic or believable sort of thing."

Most adolescents stated that they would give the "parents' section" of the booklet (Page 10, Figure 28) to their parents to read, and those who said they would not, explained their parents were already supportive. Some adolescents said that this section might compel their parents to support their involvement.

Carys (aged 17): *Yes yes, this bit is good. Like I definitely would give this to my mum to get her to like stop talking [laughs] not sure it would work, but it's good like how it says how they should support, like be supporting us, but it's good to see the doctor alone too.*
Dai (aged 17): *yeah, yup yup. I don't think like, don't think I would use it. My parents are pretty relaxed, if I wanted to make more decisions or whatever they'd say fine. It's up to me really.*

"Um, I guess I would give it to my mum because I guess it tells them how it says that you can help to support your uh daughter or son and encourage them to ask questions and that's important because then they can like speak for themselves and ask the questions that's important to them so that they know like what might happen or what's going on and stuff" (Jade, aged 13).

HCPs

Most HCPs agreed that the booklet effectively highlighted that clinicians endorse adolescent involvement. Several HCPs also stated that the booklet would help clinicians to further support adolescent participation by providing HCPs with information about their patients which could facilitate discussion, and by reminding clinicians to offer options around treatment and involvement.

"yeah but I like that it says in there that you can talk to the doctors or nurses by yourself, because we don't always remind them of that, to ask questions, and this tells them and reminds them that it is ok and they are allowed to ask to meet with the health professionals without their parents to discuss these kinds of things, and they don't always remember to tell them that" (Clinical psychologist).

"I'm not sure how many young people grow up knowing that they could ask if there's other options of treatment and things from a diabetes point of view, you know, to encourage asking about whether to use injections or a pump um rather than feeling like you're offered a pump because you're in a particularly difficult place or whatever, if you were given, or know that there is a choice I think people would automatically start feeling a bit more encouraged by that" (Endocrinology transition worker).

However, one HCP did not seem to find Pages 3 to 5 (Figure 26) useful, as he explained that clinicians already provide details about healthcare options, but did not want to encourage discussions around risk behaviour.

"if I was to talk about a pump, I would naturally go through the pros and cons of having a pump, um unless somebody said 'I'm going to a festival and I want to get pissed'......I'm not sure I should be encouraging you to ask that sort of question, which is what you're trying to get out of this isn't it. It's not that, you know, can I have a pump or can I have CGM, those are low hanging fruits, and we tend to be, well perhaps I'm wrong, but we tend to be reasonable at making sure people know what the pros and cons are" (Endocrinology consultant)

Some HCPs expressed concern that some adolescents with LTCs do not always have options concerning more serious decisions.

Ok here [Page 5] *different treatment options. One small point though the booklet seems to suggest there are different options available under nearly all circumstances. While this could be the case in some situations while others have limited options. Is there any way we could address those situations where options are limited? This is where the youngsters struggle to cope with.* (renal consultant)

Because the thing I think about is making sure people are alive, whereas the things they're thinking about: 'well, does it fit with my schedule, does it have side-effects' sort of thing and it's like: 'well it's life or death' (renal consultant)

Another important comment from HCPs was that adolescents receive support from various professionals, not only doctors and nurses, and stated that this should be reflected in the booklet.

"And then on Page 2, 'why should I read this' there's lots of reference to doctors and nurses, and then sometimes just doctors but it's um about healthcare teams because um dieticians will be providing advice and psychologists will be providing advice, physios, OTs so I, I'd keep it as generic about healthcare practitioners rather than being specific" (Endocrinology consultant)

A number of HCPs also said that the parents' section was a way to gently tell parents to refrain from dominating the discussion, which could be helpful for both adolescents and HCPs. It was added that the section should be amended to include "guardians".

"and it's nice that includes the parents um and it's nice because it's telling the parents to back off in a nice way, like just saying that ok, it is Mum and Dad and it's their son and stuff, but actually it's the best thing for them [adolescents] *and their healthcare if they're more actively involved in decisions relating to the illness, and are taking more ownership in charge of the consultant appointments, and stuff and then so parents realising that they need to take a step back"* (Renal specialist nurse).

"Now, parents' section [Page 10]. *Yes, parents are usually the ones very anxious, much more than the young people. And it can be difficult to navigate. They can get very frustrated, which is understandable, but it's difficult. This could maybe help"* (Renal specialist nurse)*.*

Parents' section

Feel free to give this section to your mum/dad to have a read.

The purpose of this booklet is to encourage and support your daughter/son to be more involved in discussions and decisions about their healthcare or treatment.

NHS bodies and patient organisations actively support the involvement of patients in these decisions, and believe it is beneficial to them and their healthcare needs.

There are many benefits of your daughter/son's involvement in the discussions and decisions about their healthcare such as; increased knowledge, confidence, and selecting care or treatment that is best suited to them.

You can help by supporting you daughter/son's involvement, encouraging them to ask and answer questions, voice preferences and speak directly to the doctors and nurses.

They may like to speak to the doctor about something on their own, which is perfectly fine, and is good practice for when they're older.

"NOBODY ELSE KNOWS WHAT IT'S LIKE NOW APART FROM YOU, SO HOW'S A DOCTOR GOING TO MAKE THAT DECISION FOR YOU?"

Figure 28. Parents' section – Page 10

6. 4.3.2.2 Shared experiences and social norms

Adolescents

Nearly all adolescents said that they particularly liked the cartoons of adolescents and quotes throughout the booklet, which were described as relatable. Although Dai (aged 17) did not feel the pictures were age appropriate "*the pictures and all that*

were a bit, I felt like it was more for um younger, younger children", the other adolescents in the focus group disagreed. Adolescents said that the booklet could help to ease the feeling of isolation that adolescents with LTCs can experience by providing relatable examples of others experiencing similar situations, and by realising that their peers may have similar concerns.

"Um, it like it makes it easier to think about making the decision when you look at the things that important to you, and it's sort of reassuring to see other people said the same things, it helps" (Liz, aged 14).

Adolescents stated that sometimes they feel alone with their condition, and particularly liked the stories of other adolescents (Pages 8 and 9, Figure 29), which they said were relatable and demonstrated how they could be involved in SDM.

"So, these are like patient, stories about patients. Yeah, I think these are good, they're very relatable, I really like the stories, especially like the first one, because obviously because I'm diabetic, in the first one um it does explain how he has a choice in like the pump and all that. Um it sort of shows that other people have the same issues um so I think that, definitely they're an important part of this booklet I think um to say that all these like, the rest of the booklet is realistic that you have a choice so yeah, I think that's good" (Ashley, aged 19)

Owen (aged 17): *like even though I don't have like epilepsy, I'm always quite nervous talking to the doctors like you can kind of relate to that and there's people like, not going through the same thing as you because it's epilepsy but can have like the same issues and then she could like get over It*
Zoe (aged 16): *And it says "I'm the one taking the tablets" so she's aware that it is her choice what she's putting in her body*
Owen: *It opens your eyes a bit, like not everyone has the perfect life, and even if you think you have it bad, sometimes you have it so much better than other people. Reading the stories of like other people if this situation who have it um, not worse, well maybe yeah worse, I guess it depends though, it all depends*
Zoe: *Yeah yeah, so true. Like I can't imagine, I know I, well like get bloods taken, tests and stuff, but I can't imagine injecting like all the time every day*

Adolescents commented that the fact that the booklet was created by other adolescents, as stated on the front page, was important. However, they noted that this should be more prominent to draw users' attention to this fact:

Eleri (aged 16): *Was this created by teenagers?*
Dylan (aged 16): *Yeah, like the quotes and stories and everything"*
Eleri: *Yeah, that's good but you need to put the writing bigger because people don't see it, and that would like make me wanna read this [yeah] [yeah]*
Dylan*: Yeah, It should say "teenagers" in bigger writing, because you can't really tell, otherwise you don't really see it*

HCPs stated that having adolescents involved in the design and having the stories come from real adolescents was pivotal in message delivery, as adolescents may not always be responsive to HCPs:

"*them saying like: 'I've actually found it really useful to talk and learning to live and speaking out about my condition, because then they help me, and I can learn and manage in the best way possible for me.' And loads of healthcare professionals can say that to them, but unless it comes from somebody who understands what it's like to have this chronic illness, this long-term condition, it won't mean anything.*" (Neurology specialist nurse)

"*The fact they've been involved in the design is useful with the quotes and stories, gives the impression there are a lot of young people in the same boat as them, and this is coming from them, not just us*" (Neurology specialist nurse)*.*

Teenagers with long-term conditions speak about their experiences being involved in decisions with healthcare profressionals...

"HAVING A SAY HELPS YOU LEARN TO LIVE WITH YOUR CONDITION IN A WAY THAT YOU CAN, IN THE BEST WAY POSSIBLE"

I was diagnosed with Type 1 diabetes when I was a baby. I was injecting insulin up to 5 times a day. I didn't like having to leave class to inject, and felt awkward doing it in front of my friends, so I sometimes missed injections. I brought this up with his doctor, and we discussed the option of trying an insulin pump. I wasn't sure at first because I met a guy who had one, and he didn't get on with it. But we decided I would give it a go, and it turned out to be a really good option for me. I was glad to have a say in that decision

Rhys, aged 15

I was diagnosed with epilepsy 6 years ago. Last year, I had to change medications because I was having more seizures than before, I think it might have been due to the stress of GCSEs. I didn't think changing medications at this time was suitable personally, but I wasn't really involved in that decision because I was feeling really tired during the appointment, and preoccupied with my exams. It didn't really turn out well, and at the next appointment I spoke with my consultant and we decided to change again. I'm the one taking the tablets, so I think it's important that I'm involved in deciding if I actually wanna go on a certain medication or not. It was much better that I was involved in the decision of coming off the one and starting a new one, and I was happy about that.

Aamaal, aged 17

I've had arthritis for 2 years. At first, I felt quite nervous talking with the doctors and nurses, and would rather my parents do it for me. But then I realised it's better for me to participate because it's about me. It could affect my school, or other parts of my life, like playing guitar, and my parents didn't always get it right. Now I try to ask as many questions as I can, try to get myself more involved, and speak to the doctor myself instead of getting somebody else to speak for me. When I ask questions, the doctors answer them, they don't mind me speaking, they like that I'm involved, and I feel like I have a say"

Carys, aged 16

"DON'T BE AFRAID TO SPEAK OUT/ASK QUESTIONS"

Figure 29. Adolescents' stories - Pages 8 and 9

6.4.3.3 Motivation

Participants discussed how the booklet highlighted positive aspects and recounted positive experiences of being involved in SDM, as well as tackling some of the emotional barriers to involvement and thus contributing to motivation around participating in healthcare discussions and decision-making.

A key theme identified across the dataset related to messages about adolescents having the "right" to be involved in SDM relayed throughout the booklet, particularly in the "why should I read this" section (Page 2, Figure 24) and the "questions and concerns" section (Page 1).

Adolescents

Adolescents described the booklet as empowering and said it provided them a sense of authority over their healthcare decisions:

Eleri (aged 16)*: It's good, it's good. It's saying how like what you say is important like we shouldn't just be in the side-lines, but also like we don't always have to say anything, sometimes I just don't feel like it you know? Like if I'm just tired or fed up or whatever, maybe other things on my mind and just don't want to think about it then, but it's good here it says how like, how that's ok. And just because we say or don't say this time, doesn't mean we want to the same next time, depends on the day, depends how I'm feeling but like it says, it's up to me um-*
Lowri (aged 16)*: Yeah, yeah I think it's definitely come across that you're the one in charge, you don't have to, you can let someone else do it but um you'd, they* [the decisions] *can be better and easier for you sometimes if you're more involved, in your own choice [yeah]*

Adolescents particularly liked the use of lettering style (bold font) to draw attention to the fact the decisions were about them:

I think throughout the book it's just, it's always directed to 'you', 'your' in bold and that's just really good, it's put it into perspective that it is your decision at the end of the day, and no one else can make that decision for you. (Carys, aged 17)

Eleri (aged 16)*: Yeah, and I like how it's in black as well, like "you" and "your", it's like um, like empowering*
Dylan (aged 16)*: Yeah, I like that, how the "yours" are in bold*

Evan (aged 14) commented that having the physical booklet to bring into the consultations could help enable him to be firm on his preference:

"Yeah, really useful actually to look at these two pages [4 and 5] *I would fill it in and take it in to the doctor's with me because I could compare between them both and anything that's um anything if it's like two or more on there that don't fit in with this or this* [risks/benefits] *then I could like say no to it and I have this to justify"*

However, some adolescents stated that the word "teenager" has pejorative connotations and said that the terms "young people" or "young adults" were more empowering as illustrated in the following extract from the focus group discussion:

Seren (aged 17): *adults kinda use teenager as like "oh just being a teenager"* [yeah]
Zoe (aged 16): *My brother does it to me and he's like 4 years younger than me*
Dylan (aged 16): *I'm fine with being called a teenager because that's what I am*
Owen (aged 17): *You could use 'young people'*
Seren: *yeah, maybe something like 'young people'*
Eleri (aged 16): *Or just 'people"*
Owen : *But they're talking about young people, so I think like young people I like that* [Yeah]
Zoe: *Yeah, or maybe 'young adult'*
Seren: *I think that's more like -*
Zoe: *like more mentally-*
Seren: *Like more maturing, um it makes you feel, it makes you feel more mature and more, and I think in this situation as well it makes feel you more-*
Owen: *'Big Child [laughing']*
Dylan: *I prefer 'teenager' to 'child'*
Eleri: *Definitely not 'child', 'young adult'!*
Owen: *Yeah, like 'young adult' is like you're capable of making the decision as well*
Lowri: *It might make you feel something more, make you more likely to do it if they consider us a young adult, not a teenager, give us more responsibility* [Yeah yeah]
Zoe: *I feel childish if you're a teenager. A bit like you can't make the decision* [yeah]

The issue surrounding the implications of the term "teenager", and preference for "young adult", which is perceived as more empowering, was also noted in other groups.

"*But sometimes, like the word 'teenagers' you know, like yeah, I know we're teenagers but I guess I would say sort of young adults is more um, um a thing that is said now. I think because, oh they say like 'oh teenagers….' like in a negative way, young adults is a bit sort of like more about confidence and control*" (Carys, aged 17).

HCPs

HCPs reflected on how adolescents sometimes demonstrate difficulty being involved in discussions and asking questions, which could be addressed by the booklet:

"*So, you know I think a lot of young people need be able to say: 'sorry, can you repeat that, or can you explain that differently to me' especially if there's, if we're talking about terminology that they're not particularly used to. Like if it's a new health condition um you know I, I would love for more young people to realise they can stop and say: 'wait, can you tell me what that means' or 'can you tell me why this is happening' you know, so 'It's my body, I can have a say' It's just automatically saying: 'I can, this is something that I can do' rather than 'you can't', it, it's really empowering so yeah I liked it.*" (Neurology specialist nurse)

One specialist nurse also noted that the booklet could act as a prompt to help HCPs to give adolescents more control by eliciting discussions around involvement preferences.

" if health professionals go through this with a young person as well, it might be quite a good prompt for that health professional to bear in mind that, firstly they need to ensure that everything around the options is properly explained, but also that they may not want to actually talk about this, and some things could potentially upset them, so they can have this conversation and it gives them [adolescents] *that power".* (Renal specialist nurse3)

Some HCPs expressed a concern about a response to one of the concerns on Page 6 of the booklet about making the "wrong" decision (Figure 27). They explained that adolescents with LTCs should not have to wait until their next appointment to make amendments to any healthcare plans that are not working for them, and that adolescents should feel empowered to instigate that change when they feel it is necessary:

"here is says: 'your decisions can be changed the next appointment' that, I might be being well, but that goes against SELF-management, if you need to wait until your next appointment." (Endocrinology transition worker)

6.4.3.3.2 Perceptions, attitudes, and outcome expectations

Adolescents

Adolescents said that the booklet could be successful in changing feelings and beliefs around being involved in healthcare decision-making. Several adolescents stated that the booklet content could make them feel less worried and more positive about participating in discussions and decision-making with HCPs:

Liz (aged 14)*: yeah, I would worry about that because if you make the wrong decision and something goes wrong it's your fault because you decided, and it was wrong so-*
Jade (aged 13): *Um, yeah, I worry sometimes because like if you make the wrong decision it can have like, it, you can collapse and you might have to go to hospital, but maybe then if you have like any doubts you could ask your doctor like what would be best*
Liz: *Yeah, it's good like here it says, because you realise they* [HCPs] *won't give you a decision that's wrong, and like if you don't like it you can change it, so I'd feel good about that, like less scared.*
Jade: *Yeah, makes you feel better. I like it* [the booklet] *because it's like you don't have to because sometimes you really just don't want to. But you, it's good for you because then you know what's going to happening, you're always like more in control and that's a positive.*

Adolescents stated that the booklet was effective in highlighting and drawing awareness to the benefits of SDM:

Lowri (aged 16): *I think it's definitely come across that you're the one in charge, you don't have to, you can let someone else do it but um you'd, they, the decisions, can be better and easier for you sometimes if you're more involved, in your own choice*

Zoe (aged 16): *Yeah, If you're more involved the treatment will be more suited to you than if you weren't*
Lowri: *yeah yeah, and it's good for me, and good for the decision*
Zoe: *like in order for it to be the best decision, I need my say as well, it like makes you feel like what you have to say is important*

HCPs

HCPs also stated that the booklet relayed positive messages and discussed how SDM can be beneficial for clinicians as well as patients.

"it's saying, you know it, it's good for them to be involved, it benefits them, and useful for us, as in we want them to understand everything, speak up, ask when they don't know. Ultimately our job is to keep them as healthy as possible, but they need to get on board with it all, treatment and the like". (Clinical psychologist)

6.4.3.3.3 Personally relevant and bespoke

Adolescents

Adolescents appreciated how the booklet could be individually tailored to them and their needs by enabling them to select from a list of preferences around healthcare options (Page 4), or add their own, and complete the text boxes with information about the options available to them (Page 5). The booklet was described as "personal":

Ashley (age 19): *And um it's like personal, about what's important to me, it's all relevant really, I can um I can identify with a lot of these*
Dai (age 17): *Especially um like best fits in with my schedule, if you do sport and stuff or have a job like and you need to inject and stuff or whatever medication, you need it to work around your schedule. I prefer to go in first thing. This helps you like think about that because sometimes at the time, at the appointment you don't think about these things to say.*

Jade (aged 13) described how completing the tasks in the booklet, particularly the checklist on Page 4 alongside the table on Page 5, tailors the selection process to that individual, enabling deliberation and the selection of the best option for them. Evan agreed, but suggested for a key healthcare issue to be added to the list of preferences.

Jade (aged 13): *So like looking at this, comparing the two I think the injections is still the best option for me, like on this page* [Page 4] *I picked less obvious or more normal so if that's what's most important for me, then having something that's not on me all the time is the best option for me in that case, it's good to do this, like fill it in because you can see how different options are better for different people.*
Evan (aged 13): *You should also add painless because I um because I have a low pain threshold, so I feel pain a lot, quite easily. I had the omni pods then sometimes*

depending on where I put them, sometimes I've caught veins and it's bled a little after I've taken it off. And there was one time where I caught a vein quite badly in my stomach and when I took it off there was a lot of blood and it hurt so bad.

Most adolescents did not have an issue with the booklet format and said they would have sufficient time to read it while waiting to see the different members of their clinical teams.

"um so if these sort of things, like the booklet if it's something they give you in clinic or stuff like that I feel like when you're waiting in clinic and stuff like that you always pick up a booklet, you always read something. As much as an app or you know like on the phone is helpful um when you're in clinic there's always a waiting time, you always pick up something to read, so I think um these are still relevant, like the little booklets and stuff, they're still relevant, it's something to do, something to think about while you're waiting. And obviously like you said then it's got the question section, um you probably wouldn't normally consider uh writing down questions before you've gone into an appointment, and it gives you the opportunity to think about that, so yeah" (Ashley, aged 19)

However, several adolescents also mentioned that the option of an additional format for the intervention would be beneficial:

Owen: *like I probably would if I was just waiting around, I pick up a booklet and have a flip through if it looks interesting*
Eleri: *Yeah, like anyway I never get data in the hospital [No, No (laughing)]*
Owen: *No bars! me neither*
Eleri: *Yeah, bars. Because if it said that question [booklet title] and I could see that it was for teenagers, then I would. Because I get bored in there so I'm just like –*
Lowri: *yeah, I'd probably like read it because I get bored, so I like, normally like read all the adverts on the walls, or like that come up on the TV. So maybe if it was like an advert on the TV, if you're just looking up, like into space, or like a video. I might be more likely to read it then*

Adolescents stated that an online version of the booklet would be useful for subsequent consultations as they felt they would be unlikely to return to secondary care clinic with the paper copy.

It was said that the booklet could have a wide reach due to the diversity of the adolescents pictured and described.

"I think it's really good because it shows different people on the front instead of them all being like looking the same and being one person, there's loads of different ones to show it's not just one type of person who has a condition, it can be like different people, yeah I do like, I do like the pictures." (Liz, aged 14)

Several HCPs also said that the booklet could potentially help clinicians to tailor their care delivery to adolescents with LTCs, with an individualised approach:

"Um and everybody with a long-term condition is going to experience it individually um and practitioners need to take into account the individuals, not just the condition. We started using 'ready steady go' [transition resource]*………… um but this* [the booklet] *is, this is more open, which I like. Because actually their concerns might be a little bit different, and instead of having it there for them already like in the 'ready set go' booklet, they fill it in themselves so I like it is more personal that way, more on them, so to speak, and can help us be more um patient-centred. And the fact is written by young people it's much more young people friendly than the 'ready steady go'".* (Clinical psychologist)

"I could see us; I could see it being a really useful tool in our clinics just to kind of start those conversations off really. Um if someone were to come up and they've given me this and they'd ticked several of these points, it would be a lot easier than just starting up a random conversation um about them looking after their own healthcare. Also, if I knew where they were coming from already, where their head was at with it, how much they were kind of wanting to kind of get involved in making those decisions, I think it would be really helpful and um I think we'd probably have a better outcome in terms of getting them a bit more engaged and a bit more involved going forward" (Neurology specialist nurse)*.*

Similar to the adolescent participants, HCPs expressed concern around only having the intervention in booklet format, which does not provide adolescents the option if they would prefer to access the information in other media. This was said to make the intervention less accessible to patients who have difficulty reading or prefer not to.

Endocrinology consultant: *if I was given that in a waiting room, that would take me 20 to 25 minutes to read that, Or longer. And I'd probably get put off by all these colours at the beginning anyway, and probably not getting much beyond page two or three. because it's quite, it's quite a lot of information there isn't there, I suppose for people to read that in 5 minutes, it's quite a lot to take in I think that a teenager would be more likely to engage with it if it was, or at least if they had the option to have I don't know maybe a video or something they can listen to or-*
Endocrinology specialist nurse: *Putting it on YouTube*
Endocrinology consultant: *Yeah, what would be nice is to have, is to have a spoken version as well, that there's an easy link that somebody can type in*
Clinical psychologist: *a QR Code*
Endocrinology specialist nurse: *a QR code, and then it goes straight to teenagers reading this leaflet, different teenagers, so you've got different voices reading elements of the leaflet out. But either way, it's definitely something we can give out and try, some will use it some won't"* [yes, yes definitely]

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6.5 Discussion

6.5.1 Key findings

The aim of this chapter was to pre-test the '*It's my body, I can have a say*' booklet with adolescents with LTCs (users) and HCPs in order to explore their reactions and views around the booklet content, design, and implementation. The booklet appears to be successful in addressing the key barriers to SDM as perceived by adolescents with LTCs, which were identified in previous Chapters.

Both adolescents and clinicians responded positively to the booklet's key messages and design, with minor suggestions for changes. Adolescents and clinicians stated that the booklet could help adolescents feel more confident about being involved and increase SDM knowledge by breaking down and simplifying the process. They felt the booklet clarified that HCPs want adolescents to be involved and could act as a prompt to help HCPs to facilitate involvement and help parents to support their child's involvement with the parents. They also felt the booklet outlined the positives of SDM involvement, with the message coming from adolescents with LTCs who may have shared experiences, and can help personalise healthcare delivery.

However, some HCPs felt that the booklet does not cater to patients with more serious conditions, for whom they believed there are no decisions. In addition, some HCPs did not want to promote asking questions around unsafe behaviour, such as consumption of drugs and alcohol, whereas adolescents would like to be able to have these discussions. Also, some HCPs felt there would be insufficient time for adolescents to read the booklet while waiting for their appointment, however, the adolescent participants did not believe this to be the case.

From the systematic review of adolescent attitudes and experiences around clinical decision-making (Chapter 2), the qualitative study exploring perceived barriers and facilitators to SDM (Chapter 4) and the Intervention Mapping exercise conducted in Chapter 5, the key drivers of behaviour were identified as knowledge; attitude, belief, and outcome expectation; social influence and skills, capability, and self-efficacy. From the framework analysis of adolescents' data, it appears that the booklet could be successful in addressing these key drivers and could potentially influence the involvement (or lack thereof) of adolescents with LTCs in healthcare decision-making.

Perceptions around adequacy of adolescents' own knowledge, contribution, and ability to be involved were barriers to involvement described by adolescents, as outlined in Chapter 4. Although the booklet, which targets adolescents with a range of conditions, could not provide condition- or option-specific information, adolescents reported that it could help them to gain this specific knowledge by using the question prompts (Page 6) and filling in the table (Page 5) with assistance from members of their clinical team. As stated by adolescents, this enables the information received to be individualised and relevant to the adolescent's specific situation and condition. Adolescents also reported that the booklet made them aware of how they can be involved in SDM by breaking down the process (Pages 3 to 5, Figure 26) and facilitating the consideration of values and preferences alongside the risks and benefits of their available options.

Adolescents said that the questions and concerns section (Pages 6 and 7, Figure 27) effectively addressed typical worries about their ability to be involved, however it was noted that it needed to be made clear that the responses in the booklet were endorsed by HCPs. As stated in Chapter 5, according to Bartholomew and colleagues (201), parameters for methods to change skills and self-efficacy include a credible source.

As described in Chapter 4, adolescents with LTCs do not want to feel differentiated from their peers, which can result in avoidance around their condition in attempt to regain a sense of normalcy, thus inhibiting their involvement in treatment or care decisions. Adolescents stated that booklet had encouraging messages which made them feel more positive about living with an LTC. They appreciate the contribution of other adolescents in the booklet development and said that the stories of other adolescents demonstrated the benefits of being involved in SDM. Adolescents also said that they appreciated the fact that the booklet was personal and could be tailored to them, their own lives, and individual needs.

Another key barrier to adolescents' participation in SDM is the belief that parents, and HCPs have authority over their involvement, and that they do not have control over the decision-making processes (see Chapters 2 and 4). The booklet appears to be successful in providing adolescents with LTCs with a sense of empowerment. Adolescents said that the booklet contained clear messages that they have control

over their involvement, and that HCPs want them to be involved, which could enable adolescents to exert control over the decision-making process when they want to.

However, the messages in the booklet need to be paired with HCP willingness to support adolescent participation (415). Two HCPs stated that in some 'life or death' cases adolescents do not have a choice. It is important to note that both participants were paediatric nephrology specialists whose patients' conditions, such as end-stage renal failure, can be severe and life-threatening. One of the key findings reported in Chapter 2 is that adolescents with LTCs with more serious outcome possibilities (e.g., cancer) reported less involvement in the decision-making process and often stated that treatment "had to be done" (204, 230). It is obvious that HCPs are concerned for their patients' welfare and are dedicated to helping them to achieve the best health outcomes.

However, as discussed in Chapter 4, perceived lack of control can result in adolescents disengaging from discussions and taking complete control over the decision. Without HCPs' input in the decision-making, there can be very serious repercussions. For example, an adolescent with epilepsy (Stephanie, described in Chapter 4) reported that she took the decision alone to stop taking her medications completely because she felt she had no control. This resulted in her seizures worsening in frequency and severity. It can therefore be critical that adolescents do feel they have some element of control, and HCPs need to consider the many ways adolescents can participate and allow choices where possible (e.g., timing and administration of kidney dialysis). Coyne et al. (230) stress that HCPs need to adopt an individualised and flexible approach so that adolescents, including those with severe conditions, can be involved in the decision-making process as and when they prefer.

Joseph-Williams and colleagues (92) report that HCPs' beliefs that they "already do this" is a barrier to SDM, and advocate for increasing HCP understanding of what SDM entails as an essential step to improve implementation. One HCP participant (Endocrinology consultant) asserted that they already provide sufficient information about options as standard care. Although HCPs often state SDM as their preferred form of care delivery and say they already use it in practice, HCPs often revert to paternalistic decision-making to 'protect' patients (416).

Additionally, It has been observed that HCPs often fail to elicit preferences of adolescents with LTCs, and typically provide detailed information about their preferred option, with less information about other options (270). As Joseph-Williams and colleagues state (92): *"Clinicians' long held commitment to doing what they perceive to be the best for their patients is a key barrier to attitudinal change. This is well intended, but fails to recognise that patients' values, opinions, or preferences are important and might differ from their own"*. Although the '*It's my body, I can have a say*' booklet is targeted at adolescents, some HCPs said that the booklet could also help them to deliver more patient-centred care by initiating discussions, prompting HCPs to provide details around options in order to help adolescents complete the 'weighing the options up' table (Page 5), and informing HCPs about their adolescent patients' preferences in the 'What is most important to me' section (Page 4). HCPs contribute to SDM by providing information about options, eliciting values and preferences and engaging patients and parents in discussions to deliberate the most appropriate option depending on individual circumstances (100, 128). From the findings of this chapter, HCPs are keen to do this and feel the booklet could have the potential to facilitate and support his process.

As discussed in Chapter 1, parents of adolescents with LTCs often assume several roles during consultations with their child's HCPs, which include advocate, expert about their child's condition and quality of life, and protector of the adolescent the family values (154). Adolescents with LTCs trust parents to make decisions on their behalf, particularly when they are feeling unable (51, 154). However, adolescents with LTCs reported that parents often inhibit attempts to participate in discussions with HCPs (see chapters 2 and 4) (204). Parents of adolescents with LTCs generally view their child's progression in responsibility for their condition as positive, but can find it difficult to relinquish control due to fear of poor health outcomes (51, 260).

Parents are seen to have their children's best interests at heart, and to act accordingly (417). Adolescents with LTCs see parents as playing an important role in supporting them, both practically and emotionally, and they look to parents for guidance and support when needed (277). Parental support can facilitate SDM between HCPs and adolescents with LTCs and increase adolescents' confidence to be involved (51, 238, 418). Adolescents with LTCs feel that parents' role should shift gradually from a position of decision-making authority to providing emotional support

and guidance in decision-making, enabling their son/daughter's role to gradually increase over time (277, 419). However, the shift in decision-making responsibility between the parent to the adolescent with a LTC has been described as a dynamic, non-linear process, dependent on contextual factors and the adolescent and parent decision preferences (51, 420).The 'Parents' section' of booklet (Figure 28) was said by adolescents and HCPs to potentially be able to assist parents to support their child's involvement. This could be particularly useful as adolescents reported that although adolescents generally want parents to be involved, parents nearly always played a larger role in the decision-making process than the adolescents would have liked (see Chapter 4) (279).

The majority of adolescent and HCP participants said that the booklet should be distributed in the secondary care clinic waiting rooms when adolescents check in for appointments. Most adolescents said they would be likely to read the booklet while they are waiting to see members of their clinical team. Adolescents can then prepare with questions for members of their team to gain information about their options. The booklet was said by both adolescents and HCPs to be able to facilitate discussion and decision-making processes during clinical encounters. The main suggestions for changes to the booklet include more appropriate language, enhancing the design to increase interest, increasing trustworthiness, and improving accessibility. These suggestions are discussed in more detail below.

6.5.2 Changes to the intervention prototype and suggestions for implementation

As a result of the intervention pre-testing described in this chapter, a number of changes were made to the '*It's my body, I can have a say*' booklet to improve acceptability by users (adolescents with LTCs) and potential implementers (HCPs). Firstly, the term "teenagers" was viewed by many adolescents as a disparaging term seen to be used by adults to 'other' them, so this was changed to "young adults" throughout the booklet, which was said to be empowering. Adolescents with LTCs also said it was important to draw more attention to the fact that other adolescents with LTCs were involved in developing the booklet and said this would make them more likely to engage with the booklet, so this was made larger on the front cover. On page 3 the colour scheme of the bubbles was changed to improve consistency and it was clarified that the information gathered as a result of the questions could be

added to the table on Page 5, as recommended by a group of adolescent participants. On page 4, "self-management" was defined as one participant was unfamiliar with the term, some wording was changed, and "least painful" was added as an option preference. On Pages 6 and 7, it was clarified that the answers to the concerns were endorsed by HCPs to improve credibility, as suggested by a group of adolescents.

HCPs noted that the term "doctors and nurses" was not inclusive of all members of the clinical teams, such as dieticians and psychologists, so this was changed to "health professionals" throughout the booklet. On page 5, HCPs said it would be useful to encourage adolescents to revisit their option choice if their confidence score was low, so this point was added. It was also mentioned that the response to the first question on Page 6 which said, "*many decisions can be changed at your next appointment*" was overly restrictive, so the response was changed to reflect this to "*many decisions can be changed if they don't work for you*". Finally, the last suggestion made by both HCPs and adolescents with LTCs was to widen access to the booklet by having it available in other mediums. So, a QR code was added to the back of the booklet which links to a short video summarising the booklet content, as well as an electronic form of the booklet (Figure 30). This QR code can, for example, also be placed on clinic posters, included on patient letters, or sent via text message appointment notifications, and enables the booklet to be accessed and distributed electronically. The video allows the booklet content, including key ideas, quotes, and imagery, to be accessed by those who may struggle to read, or may not want to read the full booklet. Furthermore, mobile application and video were the second and third most commonly suggested format for intervention delivery, following booklet (Chapter 4). Although not a mobile application, the video and booklet can be easily accessed via a mobile application (YouTube). An updated version of the booklet with the aforementioned amendments is included in Appendix 8.

https://youtu.be/DifedRtUcgo

Figure 30. QR code and video link for the "It's my body, I can have a say" booklet

As a result of the suggestions from adolescents and HCPs mentioned above, the proposed plan for implementation will be to distribute the booklets at the secondary care clinic's receptions. When the adolescents check-in to clinic, they will be given a booklet which they can read while they are waiting and complete with the assistance of their clinical team members. A more in-depth plan for implementation will be discussed more in depth in the following chapter (Chapter 7).

6.5.3 Strengths and limitations

There are a number of factors that could limit the transferability of findings outlined above. Firstly, this pre-testing involved a small sample (14 users, 13 HCPs), with somewhat homogeneous groups of adolescents with LTCs (renal or endocrinological conditions). Apart from age, sex, LTC, and time since diagnosis, no demographic data of the adolescents were recorded. However, the sample may have lacked cultural, cognitive, and deprivational diversity. It would have been useful to have input from a more diverse target user group in order to for the findings to be more widely transferable, and to ensure appropriacy of the booklet for a wider range of patients. However, a previous feasibility study, which aimed to examine adolescent patient perspectives using focus groups, found recruitment to be a major difficulty (421). Recruitment for the qualitative interviews outlined in Chapter 4 was cumbersome, with only a 29% response rate. In order to ease the recruitment process, I decided I would recruit from pre-existing groups that meet on a semi-regular basis and hold the session after one of their meetings. Nonetheless, to my

knowledge, the events were only organised for adolescents attending endocrinology and renal clinics, which limited the participants I could recruit. Adolescents with LTCs who are not afforded the opportunity to attend the meet-up events, also did not have the chance to participate in this study. This limited the opportunity for adolescents with LTCs to 'have a say' about the intervention based on their condition. Furthermore, the fact that the adolescent participants attended organised meetings, and volunteered to participate in the focus group session could reflect that they are engaged and motivated individuals who may already be more active in their care than the average adolescent with an LTC.

Due to the invitation to hold a focus group session with a paediatric endocrinology team, most of the HCP participants specialised in this area. In addition, HCPs who volunteered as participants for this study may be more receptive to SDM, and already deliver more patient-centred care than those who did not respond. It is essential to gain insight into how this booklet will be received in a real-life clinical setting. This pre-testing phase focuses on obtaining initial feedback on the booklet content and design, but testing took place in an artificial setting. Further testing is necessary to evaluate the booklet's overall usefulness and acceptability. A protocol for the pilot and feasibility testing stage will be proposed in Chapter 7, which will aim to test the booklet as it would be implemented with a larger number of adolescents with LTCs and their clinical teams.

The think-aloud technique has been used to evaluate interventions aimed at adolescents in individual qualitative interviews before (410, 411), but has rarely been used in focus groups (422). With little guidance on how to use the think-aloud techniques in focus groups, I observed difficulties with the first session, particularly because the two adolescent participants read the booklet at different paces, which limited discussion between the participants. Studies examining adolescent reading ability have found a wide variability between participants (423, 424). Therefore, I was able to adapt the process by cutting booklet into sections and distributing them piece by piece. After making this change, I observed improved subsequent session participation, enabling further discussion between participants around specific sections of the booklet.

By analysing both HCP and adolescent data together, the HCP voice may have overshadowed the voice of the adolescent which, according to the Person Based Approach, should be at the forefront of the intervention development (200). It is important to maximise HCP acceptability of the booklet in order to improve buy in, as ultimately, they are likely to be the key decision-makers as to whether and how the intervention will be implemented in a clinical setting. However, HCPs often commented on how they perceived adolescents would respond to the booklet, which should not take precedence over the adolescents' actual impressions or responses. The data from both groups of comparisons were analysed together in order to ease comparison between the two groups using the framework analysis (414). The groups have been separated within the subthemes with results from the adolescent groups first, in attempt to ensure the HCP data are not dominant. However, if the data had been analysed separately, this possible concern may have been avoided.

The framework analyses that I conducted enabled me to establish whether intervention components addressed the key barriers to SDM as perceived by adolescents with LTCs. In the booklet development, continual feedback was received by a group of adolescents who were known to me, as well as my supervisory team of SDM experts, and an illustrator and graphic designer was commissioned to develop the booklet at a high standard. However, participants were aware that I was involved in the development of the booklet, which may have increased reluctance to offer negative feedback. In attempt to overcome this potential issue, participants were actively encouraged to provide criticism to assist in improving the booklet, I emphasised the importance of their honest feedback to this project, be it perceived as positive or negative. Participants did not appear hesitant to contribute criticisms, and all were able to point out areas for improvement.

Finally, the inclusion of an HCP focus group was unplanned. It is recommended for focus group participants to be relatively homogeneous and not of differing positions of authority (412). However, in this case the session included consultants, nurses, psychologists, and a dietician. Nonetheless, hierarchical positions did not appear to affect participation in the session (e.g., equal participation between nurses and consultants), which could be because it was a close working team that hold regular team meetings and discussions. Furthermore, an intervention to prepare and support

SDM with patients could be equally relevant to all team members. In addition, holding the focus group session in one of the team's regular meeting slots also afforded the opportunity to include participants who may not have otherwise volunteered of their own accord.

6.5.4 Future research

Although ideas for implementation were elicited in the interviews and focus groups, these were not explored in depth, with only two main questions addressing implementation suggestions on the interview schedule for HCPs (Table 26). Going through the 12-page booklet took a considerable amount of time and I was conscious not to include too many follow up questions afterwards. Future research could delve into the specific details around the implementation ideas, such as who could distribute the booklets in the secondary care clinics, and how could they ensure there were copies available. This will be explored more in the implementation planning, which will be discussed more in detail in Chapter 7.

Parents were not included in the intervention pre-testing due to findings from Chapters 2 and 4 that adolescents with LTCs often wanted parents to have a lesser role in the decision-making process. However, in future it would be useful to explore parents' perceptions of the Parents' Section (Figure 28) of the booklet. This would enable an understanding of the usefulness of the page, and for changes to be made to improve acceptability. Plans for involving parents in further evaluations of the intervention will be discussed in Chapter 7.

6.5.5 Conclusion

By using a systematic and theoretically grounded intervention development process (Intervention Mapping Approach (201)), I have ensured that the intervention addresses some of the key barriers, which were identified in Chapters 2 and 4 of the thesis. The think-aloud method used in this pre-testing process meant that the content and format of the planned intervention could be tested with intervention users (adolescents with LTCs) and HCPs to explore their views and make the necessary amendments in order to improve the intervention's usefulness and acceptability prior to a more in-depth evaluation as it would be implemented.

There are several implications of this pre-testing process for specific improvements to the booklet and identifying the most appropriate implementation strategy, which will be discussed in further detail in the following chapter (Chapter7). The pre-testing described in this chapter has provided an overview of stakeholders' initial reactions to the booklet in an artificial setting. The next step will be to propose a protocol for pilot and feasibility testing of the '*It's my body, I can have a say*' booklet in a real-life environment, with clinical teams and adolescents with LTCs who are attending secondary care clinics, and who are likely to be faced with healthcare decisions in order to further understand the functioning and preliminary assessment of the effects of the intervention (Chapter 7). This will include a plan for implementation and a plan for evaluation of the process and outcomes (Stages 5 and 6 of the Intervention Mapping Approach (201)).

Chapter 7: Proposed plan for intervention implementation and initial testing

7.1 Chapter overview

Chapters 2 to 6 describe how an intervention prototype was informed, designed, produced, and pre-tested, resulting in the current form of a booklet titled "*It's my body, I can have a say*". This chapter will present proposals for further research arising from the work completed to date, but beyond the remit of this thesis. The chapter presents proposed plans for implementing the intervention for initial testing, including a proposed protocol for a feasibility study with embedded pilot randomised controlled trial (RCT) and process evaluation for intervention optimisation and to inform a full-scale RCT. This Chapter addresses Thesis objective 6 (Chapter 1, Page 21).

7.2 Introduction

Chapters 2 and 4 report a systematic review and qualitative interviews resulting in the identification of barriers and facilitators to shared decision-making (SDM) with adolescents with long-term conditions (LTCs) from the patients' perspectives. The qualitative interview study is the first, to my knowledge, to focus specifically on the perceptions around barriers with this population, and it was published in the *Journal of Adolescent Health* (Appendix 2) (279). As with the preceding review by Boland et al (193) published in the same year, which focused mostly on barriers perceived by parents and healthcare professionals (HCPs), the qualitative study highlights factors that need to be considered when trying to engage young patients in the SDM process.

The development of the "*It's my body, I can have a say*" booklet was driven by adolescents' perspectives, however, these cannot be used in isolation in informing implementation. The factors identified in my research will need to be considered in conjunction with HCP-reported barriers (193) and learning from SDM implementation programmes (92). Additionally, mutual collaboration amongst stakeholders enhances intervention implementation and evaluation, and increases the likelihood that the intervention will be sustained (425). Implementation will involve putting these pieces together in order for intervention delivery to be optimised prior to commencing the evaluation process. The Intervention Mapping Approach (IMA) will be used to facilitate the development of strategies for implementation (stage 5), as well as the

creation of an initial testing plan (stage 6) (201). These processes align with the *implementation and trailing* stage of the Person Based Approach (200) and the *feasibility and piloting* phase of the Medical Research Council (MRC) guidance (167).

According to the IMA, planning for intervention implementation involves firstly designing it in ways that enhance the potential for being adopted (IMA Stages 1 to 4, Thesis Chapters 2 to 6), then designing interventions to influence adoption, implementation, and continuation (Stage 5). Interventions cannot be effective if they are not implemented, and their effectiveness will be compromised if they are not implemented correctly. If the intervention is not sustained, it may not produce health outcomes, or if any outcomes are observed and they may be short lived (201). Careful implementation planning is essential for the intervention to be successful, and effectively evaluated (201).

Data from over 500 studies reveal that when intervention implementation is thoroughly planned, the measured outcomes can be up to three times greater (425). Structured implementation planning frameworks can help reduce the research-to-practice gap and maximise the uptake, sustainability, and impact of the intervention (426, 427). Stage 5 of the IMA, also referred to as implementation mapping, focuses on planning for intervention implementation to ensure that the intervention is used as intended during the initial testing of the intervention's efficacy or effectiveness (201).

Most of the literature around SDM implementation has focused on attempts to encourage the uptake and use of patient decision aids (103, 428-431). However, there are still no clear recommendations on how best to implement patient decision support into routine practice due to a lack of evidence of sustainable implementation (432). I will therefore propose an implementation plan for the "*It's my body, I can have a say*" booklet based on existing evidence, the IMA, and the intervention pre-testing results relating to implementation suggestions (Chapter 6). As discussed in Chapter 6, most HCPs, and adolescents with LTCs suggested distributing the booklet at the secondary care clinic reception when adolescents check in for appointments. This would allow clinic attendees to read the booklet immediately prior to, and have it readily available during, consultations with their clinical team members.

The final stage of the IMA (Stage 6) looks at developing a plan for testing and evaluating the intervention based on the five previous stages (201). The MRC guidance recommends feasibility and pilot studies to help inform the undertaking of a full-scale evaluation and identify unforeseen challenges that may occur in ensuing an RCT (1). Pilot and feasibility testing helps confirm whether the intervention is ready for full-scale evaluation by trying out the intervention as it would be implemented with users (adolescents with LTCs) and implementers (clinical teams) (433). This can serve as a trial run and can help determine if any adaptations to the intervention, or adjustments to the implementation plan are necessary. It can also ensure that those involved in executing a full-scale evaluation can be prepared to deal with any problems that arise. An accompanying process evaluation will aim to understand the functioning of the intervention, including how it can be improved (167, 434). Table 30 details the three types of evaluations outlined in this chapter.

Table 30. Pilot, feasibility and process evaluation according to NETSCC (403) and MRC (434)

Evaluation	Description
Pilot study	Testing of a miniature version of the main study to see whether the processes of the study (e.g., recruitment, randomisation, treatment, and follow-up assessments) can work together and run smoothly to inform progression to the main, full-scale study.
Feasibility Study	Assess whether a study can be done and used to estimate important parameters needed to design the main study. Examples include: the sample size calculations; participant willingness to be randomised; HCP willingness to recruit participants; number of eligible participants; follow-up rates; and time needed to collect and analyse data.
Process Evaluation	Aims to understand how and why a complex intervention works or does not work by examining the process through which the intervention generates outcomes including implementation (i.e., how the intervention was delivered), mechanisms of impact (i.e., how the intervention effects occurred), and contextual factors (e.g., individual characteristics).

7.2.1 Chapter aim and objectives

The aim of this chapter is to propose a plan for initial intervention implementation and testing. The objectives were to: (a) describe an implementation plan for "*It's my body, I can have a say*" booklet to be tested and (b) outline a protocol for a feasibility study with embedded pilot RCT and process evaluation.

7.3 Developing an Implementation plan.

The IMA outlines four tasks to devise an implementation plan to enable adoption, implementation and maintenance of health promotion interventions (Figure 31) (201).

Task 1	• Identify intervention adopters implementers, and maintainers (e.g. clinic HCPs, management and administration staff)
Task 2	• State outcome and performance objectives for the three stages of intervention use (adoption, implementation and maintainance)
Task 3	• Construct matrices of change objectives for intervention implementation
Task 4	• Design implementation interventions

Figure 31. Four tasks of Implementation Mapping (201)

7.3.1 Identifying intervention implementers

The first task in Stage 5 is the identification of all the potential adopters and implementers who will be vital to intervention implementation. Identifying the leaders within the clinical teams will be an important part of this task. A group of stakeholders at all the socio-ecological levels, including decision-makers for adoption (e.g., clinical leads) and decision-makers for implementation and maintenance (e.g., clinical team members) will be necessary for developing an effective implementation plan. Collaborative planning with a stakeholder group of administrators, HCPs, academic advisors, patients, and parents will enable the formulation of relevant and specific implementation objectives and methods (435).

Identifying barriers and facilitators to implementation may require initial brainstorming with the stakeholder group, as well as drawing upon previous evidence. Researchers argue that interventions can be more effective when tailored to different contexts (425). Group discussions will be essential to gain further understanding around the organisational structure of the individual secondary care clinics that will potentially implement the intervention, as each clinic has a slightly different organisational structure (e.g., which team members see patients and when). It is important to consider how certain characteristics of each clinic, such as size, leadership, readiness for change, and general capacity may influence intervention implementation (201). Other elements, such as feasibility within the clinical pathway, fit with the clinic's goals and values, and the capacity for change are also important factors to consider (436).

As the '*It's my body, I can have a say*' is aimed at the individual level, it is essential that the booklet is being implemented in clinical teams whose members support SDM. Otherwise, the mismatch between the messages in the booklet, such as patients "can have a say" and that HCPs "want them to be involved", and actual experiences can cause confusion and potentially reduce users' attempts to be involved in the future.

Furthermore, patient targeted SDM interventions without HCP endorsement may be ineffective (437). The 'Implementing Shared Decision-Making in the UK' report by The Health Foundation, states that doctor buy-in may be the greatest challenge for implementing SDM interventions, and stresses the importance of doctors backing SDM interventions, even if the design of the implementation programme allows for the intervention to be delivered by non-doctors (e.g. nurses) (438). According to the report, *"Physician buy-in seems largely dependent on them having 'felt the problem' and that there is a non-disruptive solution to that problem"* (p. 26) (438).

Clear communication about the importance of the intervention can influence leader support to prepare the organisation or community for implementation (436). A barrier stated by HCPs to implementing SDM in the UK is that many believe that tools are essential for SDM delivery, and that there can never be a decision aid for every possible healthcare decision (92). Although the "*It's my body, I can have a say*" booklet is not a decision aid, it was described by HCPs and adolescents with LTCs to be a flexible tool, which can be personalised around the individual patient circumstances (see Chapter 6) and could be promoted as such.

7.3.2 Stating outcomes and performance objectives

After identifying the intervention decision-makers (task 1), task 2 involves developing outcomes and performance objectives for intervention use informed by stakeholder group discussions, theoretical and empirical evidence. Bartholomew and colleagues (201) group intervention use outcomes into three stages; adoption (decision to use the intervention), implementation (the use of the intervention to a point long enough to allow evaluation), maintenance (the extent the intervention is continued and becomes a part of normal practice). In this task, intervention use outcomes and performance objectives are stated for each of the aforementioned stages. Performance objectives clarify "who" has to do "what" for the intervention to be

adopted, implemented, and sustained. Examples of outcomes include: the decision-makers at each clinic are aware of, and decide to distribute the "*It's my body, I can have a say*" booklet (adoption); the booklet is distributed as intended, and SDM is supported and encouraged by members of the clinical team (implementation); the team continues to distribute and support the booklet and SDM (maintenance).

The goal for this stage is to write a detailed plan of what needs to be done to ensure that the intervention is delivered at acceptable levels of fidelity and completeness (439). For initial implementation of a new intervention, it is recommended to place emphasis on achieving a high level of fidelity to ensure the intervention is being applied as intended (201). This involves identifying the key elements that are considered to be necessary in order to achieve intervention effects. It is important to consider and establish what constitutes fidelity in terms of intervention delivery.

As discussed in Chapter 6, most HCP participants said that the best time to distribute the booklet would be when adolescents with LTCs arrive at the secondary care clinic reception, allowing them to read the booklet while waiting to see members of their clinic team, and possibly bring the booklet into the consultation to assist the gathering of information around their options and facilitate the decision-making process. The implementation outcomes for delivering the "*It's my body, I can have a say*" booklet focus on exactly what the implementers need to do. In the case of this intervention, it could be to print copies of the booklet, ensure there are copies of the booklet available at reception, give the booklet to adolescents with LTCs when they check in for their appointment, and support adolescents' involvement in SDM, including providing information about options, eliciting values and preferences, then deliberating the options in line with adolescents' values and preferences. It will likely be different members of the team who take responsibility for the achieving the different implementation outcomes, but the individual roles should be discussed and specified within each team.

In order for HCPs to support and encourage SDM, training and familiarity with the process will be necessary. Healthcare policies, clinical guidelines and a growing body of research strongly advocate for the implementation of SDM as a key element of patient-centred care (90, 440). A scoping review found that SDM training is increasingly embedded in medical education, and most studies included in the review suggested that medical students' skills in SDM improved significantly post-training (441). None of the studies included in the review were based in the UK,

however, SDM training is currently part of the Cardiff University undergraduate medicine curriculum, with plans for SDM to be embedded in curricula nationally and integrated into the training and education for clinical professionals (442). Paediatric HCPs who received SDM training reported positive intentions to use SDM and although they did not necessarily translate into SDM use, higher intention scores were correlated with self-report SDM use (194).

Intervention maintenance involves integrating the intervention into the clinic routine. In order to consider how an intervention might be maintained, and what the performance objectives should be, barriers and facilitators of maintenance need to be considered (433). For booklet distribution and continued SDM support to be maintained, it must be seen as relevant and advantageous. HCP support will be particularly important for maintenance; without it sustained use of an SDM intervention was found to be significantly less likely (443). Therefore, performance objectives for intervention maintenance will involve feeding back any potential benefits identified in the initial intervention testing to clinical team members. Objectives may also involve later adjusting the intervention and implementation plans according to process evaluation feedback.

7.3.3 Constructing matrices of change objectives for implementation

The next task (task 3) involves developing a matrix to guide the development of the implementation intervention (201). The matrix combines performance objectives and determinants in matrices for intervention adoption, implementation, and maintenance. As with the performance objectives for health behaviours (see Chapter 5), performance objectives for intervention use have a set of determinants, or factors that are likely to influence their performance (201). The determinants address questions as to why decision-makers would decide to adopt the intervention, why implementers would do what is necessary to implement the intervention and why those responsible would do what it takes to ensure the intervention is continued over time. These are the determinants of adoption, implementation, and maintenance respectively (433).

Some of these determinants can be found in the theoretical constructs (See Chapter 3), for example outcome expectations, a construct present in Social Cognitive Theory (297) and the Theory of Planned Behaviour (295), can influence decisions around intervention adoption (i.e. if HCPs believe that the booklet will benefit their

patients, they may choose to adopt it). Other examples of determinants could be perceptions around the booklet characteristics; familiarity with the booklet as well as SDM; ease of booklet production and distribution; self-efficacy and skills around implementation; and values supportive of the intervention goals (to prepare and support adolescents' involvement in SDM).

To provide an exemplar of matrices of change objectives, I drew upon the results of two published studies to develop the determinants for adoption, implementation and maintenance: a systematic review of barriers and facilitators of paediatric SDM (193), and a publication describing the learning around implementing SDM in the UK National Health Service (NHS) (92). These studies were selected to provide UK-relevant and population-relevant examples of SDM implementation. I then mapped the key barriers to SDM implementation described in both papers on to the Theoretical Domains Framework (TDF), which was utilised in intervention development (Chapter 5). The determinants for the exemplar matrices of change therefore include skills, belief about capability, behavioural regulation, and belief about consequences (Table 31).

Table 31. Barriers and facilitators of SDM implementation mapped onto the TDF domains

Challenges to SDM implementation in the NHS (92)	Barriers/Facilitators to Paediatric SDM (193)	TDF Domains (202)
We do not have the right tools	Access to tools, resources, or training	Belief about capability/ skills
We do it already		Behavioural regulation
How can we measure it		Behavioural regulation
We have too many other demands	Insufficient time due to heavy workloads	Belief about capability
Patients do not want it	Parents and children prefer patriarchal approaches	Social influences
	HCPs lack skills	Skills
	Lack of options	Belief about consequences

Achieving the performance objectives for intervention use can also be influenced by social or structural factors of the individual clinics, which may act as barriers or facilitators. Examples could include resources for printing, time, support of the booklet and SDM, and reinforcement. The process for selecting the determinants of intervention use would involve brainstorming with the stakeholder group to develop a list of factors that can act as barriers or facilitators to accomplishing the performance objectives; reviewing the theoretical and empirical literature to refine or add to the list; and collecting new data from potential intervention adopters or implementers (201). Further research is often needed to assist the implementation process (169).

This process is very much like the selection of the health behaviour determinants as described in thesis Chapter 5. The matrices of change objectives cross performance objectives with personal determinants (barriers/facilitators to implementation). They answer the question: *What has to change in this determinant in order to achieve the performance objective?* Table 32 provides an example of matrices of change objectives, which would be subject to expansion and/or modification resulting from stakeholder group discussions.

Table 32. Examples of Change objectives for implementing the "It's my body, I can have a say" booklet

Personal Determinants: Adopters and implementers (clinical teams)					
Performance Objectives	Belief about capability	Belief about consequences	Skills	Behaviour regulation	Social Influences
PO1 Agree to distribute the booklet	BA1 Expect that they will be able to work the booklet into the existing clinical pathway	BA1 Expect that the booklet will benefit their patients	S1 Demonstrate skills to respond to what is expected by booklet distribution (increased patient activation including asking questions and desire to be involved in discussions and decisions)	BR01 Identify a need for the booklet	SI01 Recognise that others (e.g., patients, parents, team members, administrators) support the booklet and SDM
PO2 Distribute booklet when patients check-in	BA2 Expect that they have the resources to have available copies and remember to distribute the booklet	BA2 Expect that patients will read the booklet		BR02 Monitor booklet distribution	
PO3 Provide information about options including risks and benefits	BA3 Expect that they will be able to provide information about options, and have the tools needed	BA3 Expect that providing information about options will benefit patients	S3 Demonstrate skills to provide information about options	BR03 Reflect on information provision	SI03 Recognise that patients want information about options
PO4 Discuss options in line with patient preferences to come to a healthcare decision	BA4 Expect that discussions around options can be done, and within the allocated time	BA4 Expect that discussions with patient will result in selecting the best option for the patient	S4 Demonstrate skills to hold discussions around options	BR04 Reflect on discussions around options	SI04 Recognise that patients want to be involved in discussions and decision-making

7.3.4 Design Implementation Interventions

The final task in Stage 5 of the IMA is to choose change methods and practical applications, design the scope and sequence, and produce materials for an implementation intervention to influence intervention use (201). This is much like Stage 3 of the IMA (Chapter 5) where theory-based methods and practical applications are selected. In this task, information from the previous tasks is used to select implementation methods and practical applications. In the example below (Table 33), theoretical methods were selected from a list based on the determinants or change objectives for each stage of implementation (adoption, implementation and maintenance), as outlined by Bartholomew and colleagues (201). Practical applications were then proposed according to the determinants and change methods to provide an exemplar implementation intervention plan to be discussed and

adjusted with stakeholder input (Table 33). As it is the clinical teams that will ultimately decide whether to adopt, implement, and maintain the intervention, adolescents and parents are not included in this table. However, adolescents and parents should be included in the stakeholder group discussions to help advise, inform, and be involved in the decision-making regarding the implementation plan.

Table 33. Example of an Implementation Intervention Plan for the "It's my body, I can have a say" booklet

Stage	Agent	Determinants/Change objectives	Theoretical change methods	Practical Applications
Adoption	Decision-maker (clinical team leader or administrators)	Belief about capability Belief about consequences Skills Behavioural regulation Social influences	Information Information about others' approval Persuasion	Distribution of information (E-mail, distributed materials) regarding potential booklet benefits, and myth busting.
Implementation	Clinical teams Research partners	Belief about capability Belief about consequences Skills Behavioural regulation Social influences	Information Information about others' approval Information Persuasion Skill building and guided practice Goal setting Self-monitoring behaviour	Introduction meeting with team which includes skills training, and discussions around roles and performance objectives (i.e. SDM Train the Trainers programme (444)). Ongoing consultations and support including opportunity for continued training
Maintenance	Clinical teams Decision-makers	Belief about consequences Behavioural regulation	Self-monitoring behaviour Information	Team meetings, Delivery of initial testing feedback

In the intervention adoption stage, a campaign should inform decision-makers about the booklet, including positive patient responses to the booklet (from pre-testing), potential benefits to patients (e.g. possibility of adolescent empowerment and increased involvement), and addresses misconceptions around SDM, such as not having enough time (445).

Themes around adolescents' experiences with healthcare decision-making (see Chapters 2 and 4) and the booklet's potential to address the reported issues, as presented in findings of the pre-testing (Chapter 6), can be disseminated to clinical teams, emphasising that distributing and using the booklet should cause minimal disruption to clinic operations. HCPs are likely to respond positively to SDM interventions if they think it will benefit their patients without causing them additional time or trouble (438).

At the implementation stage, a meeting could take place with clinical teams, with SDM skills training and discussions around explicit individual roles within the teams.

Discussions around roles of all implementers can be facilitated at the introduction meeting in attempt to obtain collaboration within the teams. This needs to include who will be responsible for ensuring that copies of the booklet are available and distributed to adolescent patients. Discussions should also be held in order to ascertain which problems HCPs may find difficult and time consuming regarding implementing the booklet so strategies can be designed to ease this process. Resource and time pressures could be possible barriers to implementation, for example the time and resources for printing the booklets, or increased demand for discussion from patients taking more time during consultations. When exploring implementation of a patient decision aid, nurses and administration staff reported an increased workload, but they were positive about the intervention, saying it enhanced their ability to inform and engage patients (431).

HCP training on how to use the booklet and deliver SDM with adolescent patients will be necessary so that HCPs feel ready and capable. HCP SDM training should include how to 1) introduce patients to their new role as partner in decision-making, 2) provide prompts to help make it clear to patients that they want them to be involved and 3) tailor the deliberation process, including information provision and elicitation of preferences to patient literacy and readiness levels (96) (p22).

Furthermore, in adolescent chronic care, HCP training should include fostering parents to support their child's autonomy and involvement (279). Opportunity for continued SDM skills training should be made available to clinical teams (194). HCPs should be provided with tools to reflect upon and evaluate their use of SDM. Measuring SDM performance and creating a feedback loop guide will help to drive implementation, facilitating opportunities for learning and team accountability (96). There is a broad range of instruments developed for measuring SDM processes, but most of them have been developed for research, and are not necessarily relevant for a clinical setting (446).

Cardiff University, in collaboration with Making Choices Together and Public Health Wales, designed the *SDM Train the Trainers Programme* to provide HCPs with the necessary knowledge, tools, and resources to deliver SDM with patients (444). This is a one-day workshop which provides an in-depth understanding of what SDM involves with evidence-based rationale and practical application. The "diagnostic exercise" in this interactive workshop encourages HCPs to reflect on barriers to SDM implementation within their clinical teams and identify possible solutions. The final

task is to devise an implementation plan including specifying exactly how they will embed SDM into the care pathway and how it will be measured. This facilitates a set of relevant and effective performance measures to be agreed upon and established within the individual teams to determine whether their SDM objectives are being achieved. The workshop also enables attendees to train team members who did not attend, such as new members of staff.

Once the plan for initial implementation is in place, it will be suitable to proceed to the research stages. Feedback from these stages can be fed back to the clinical teams to promote intervention maintenance. A meeting can be held to discuss any ongoing team issues, reflect on self-assessments, and deliver evaluation feedback, including possible suggestions for amendments to the intervention and/or implementation. In order to improve sustainability, once the booklet has been initially implemented, any positive outcomes found after the preliminary testing can be fed back to the decision-makers.

7.4 Proposed protocol for a feasibility study with embedded pilot randomised controlled trial and process evaluation of the "*It's my body, I can have a say*" booklet

The Person Based Approach suggests evaluating interventions in real-life context(s) using mixed methods process analysis to identify further modifications to improve intervention acceptability, feasibility, and effectiveness for future implementation (200). The MRC guidance recommends undertaking feasibility and pilot studies to identify problems that may occur in an ensuing RCT, and recommends objectives to test procedures for acceptability, estimate likely rates of retention of participants and calculation of appropriate sample sizes (169, 447). Views around what constitutes a pilot or feasibility study are diverse (447). The National Institute for Health Research (NIHR) Evaluation, Trials and Studies Coordinating Centre (NETSCC) define feasibility studies as those which estimate important parameters that are needed to design the main study in order to answer the question "*Can this study be done?"*(403). Examples include willingness of patients to be randomised, willingness of HCPs to recruit participants, number of people eligible to participate, follow-up rates, response rates and adherence/compliance rates. Feasibility studies may have no plan for further work and their aim is to assess whether it is *possible* to perform a full-scale study (448).

The NETSCC define a pilot study as a miniature version of the main study which is run to determine whether the components of the main study can all work together (403). NETSCC suggest that a pilot should focus on the processes of running the main study to ensure the mechanisms of recruitment, randomisation, treatment, and follow-up assessments, and inform whether and how to progress to a full-scale trial. However, it is not possible to apply mutually exclusive definitions for "feasibility" and "pilot" studies consistent with the literature, and it is suggested that they be conducted simultaneously, without explicit distinction between the two (447).

A Process evaluation accompanying an RCT aids evaluation of the effectiveness of an intervention, including why the intervention might or might not have been effective and how it can be improved (169, 434, 449). At the feasibility and pilot stage, a process evaluation plays a vital role in understanding the feasibility and functioning of the intervention, assessing acceptance, and enabling optimisation of intervention implementation, design and testing (450).

Following the IMA Stage 5 (Implementation) steps increases the likelihood of developing implementation strategies that address the identified barriers and enable implementation (435). However, it is essential to evaluate whether or not these strategies lead to intended adoption, implementation and maintained outcomes. Stage 6 of the IMA is used to plan the evaluation of both the programme itself and its implementation plan by completing four tasks (Figure 32). The product of Stage 6 of the IMA is a plan to guide the process evaluation, which assesses the extent to which the implementation strategies fit within the context, are delivered with fidelity (following protocol), and address the identified needs (201).
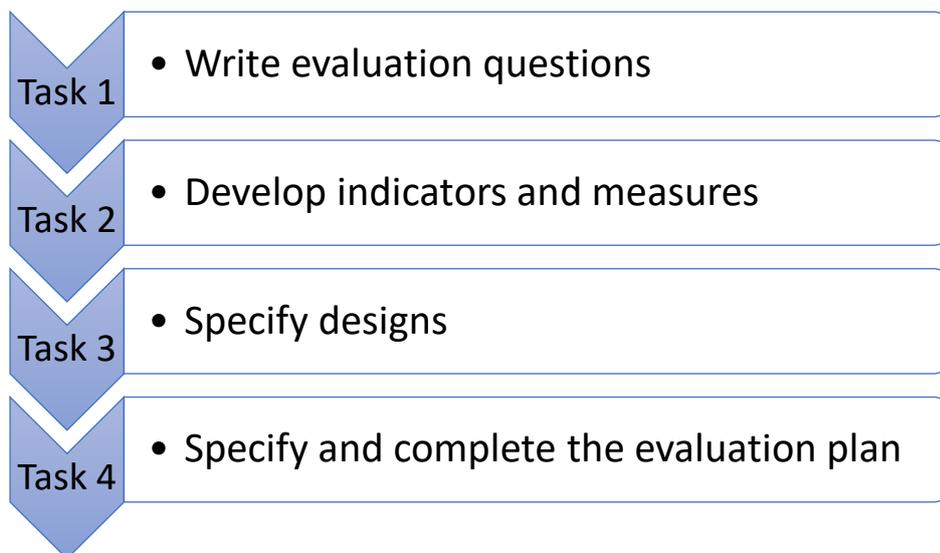
Figure 32. The four tasks of developing an evaluation plan

A process evaluation is defined as a study that aims to understand the intervention functioning by examining implementation, mechanisms of impact, and contextual factors (451). This is essential to understanding the potential link between the implementation of the intervention which has been envisaged and the outcomes that are measured (201). The evaluation plays a vital role in understanding acceptability around all aspects of the intervention, which impacts the likelihood of effectiveness and successful implementation (452).

The MRC process evaluation guidance provides a framework which describes the main aspects of an intervention that a process evaluation might investigate, such as the intervention implementation processes including fidelity (was it delivered as planned?), reach (whether/ how the intended participants interacted with the intervention) and dose (how much of the intended intervention was received?); mechanisms (or theory) of impact (how the delivered intervention produced change in recipients); and the impact of context on how the intervention works (434, 451) (Figure 33). As with all the stages of the IMA, stakeholder involvement is the key to success at this stage. This includes administrators, HCPs, academic advisors, patients, and parents.

Context
Contextual factors that shape theories on how interventions work
Contextual factors that affect (and may be affected) implementation, intervention mechanisms and outcomes
Causal mechanisms present within the context which act to sustain the status quo, or potential benefits

Description of intervention and its causal assumptions

Implementation
- Implementation process (how delivery is achieved, training, resources etc.)
- What is delivered: fidelity, dose, adaptions, reach

Mechanisms of impacts
- Participant responses to and interactions with the intervention
- Mediators
- Unexpected pathways and consequences

Outcomes

Figure 33. Process Evaluation Based on the MRC guidance (451)

7.4.1 Evaluation Questions – proposed aims and objectives

The proposed protocol outlined in this chapter includes a feasibility study with imbedded pilot RCT and process evaluation. The primary aims of the study will be to assess participant eligibility, recruitment and retention rates; to collect data to inform power calculations for the definitive trial; to explore the feasibility and acceptability of the intervention and of trial procedures; to explore the "active" ingredients of the intervention; to assess the implementation process; and examine how external factors influence the delivery and functioning of the "*It's my body, I can have a say*" booklet within the context of a secondary care clinic for adolescents with LTCs. Table 34 specifies the proposed protocol objectives aligned to the specified assessment (pilot, feasibility, or process evaluation), and how the objectives could be assessed. The secondary aims will focus on the outcomes of receiving the intervention, such as SDM involvement, decisional conflict, and quality of life.

Table 34. Study objectives and assessment methods

Study Primary Objectives	Assessment type	Assessment Method(s)
To estimate the eligibility rates among the clinic patient population.	**Feasibility study**	Based on recruitment flow chart - Eligibility rate from the clinic
To assess patients' willingness to enter the trial	**Feasibility study**	Based on eligibility data - Participants consented as a proportion of those eligible.
To estimate the recruitment rate; can 80 eligible patients be recruited in a 6-month period?	**Feasibility study**	Based on recruitment data -Recruitment completion rate
To ascertain the randomised group contamination rates (i.e. the extent of cross-over between the two arms of the trial).	**Feasibility study**	Based on protocol deviations data- xx% of those in interviention/control group who received the correct booklet
To assess participant retention rates	**Feasibility study**	Based on Recruitment data- Particiapants recruited compared to total completed
To estimate the standard deviation of the SDM outcome measures to input to the sample size calculation for future dinfitive trials	**Feasibility study**	Based on the outcome measures' effect size, SD and confidence interval
To assess whether the pilot should progress to a full-scale RCT	**Pilot RCT**	Based on the external pilot progression criteria.
To assess intervention Implentation (fidelity, dosage and reach)	**Process evaluation**	Recordings of consultations Team notes Interviews and focus groups – questions around implementation Rates of participation/eligibility
Evaluation of mechanisms of impact (the mediating factors that produce the outcome)	**Process evaluation**	Interviews and focus groups – questions around changes to potential determinants of behaviour (e.g. knowledge, social norms)
Evaluation of context (the environment and its characteristics)	**Process evaluation**	Interviews and focus groups – questions around how the intervention functions within the context of the secondary care clinic
Appropriateness and Acceptability of the intervention and implementation	**Process evaluaion**	Interviews and focus groups – questions around acceptability including suggestions for modifications. Calculation of delivery costs

7.4.2 Methods

This section outlines the proposed methods for the protocol. Once a protocol has been finalised, ethical approval will need to be sought and obtained from the NHS Research Ethics Committee, as well as the Research and Development teams of the relevant health boards (i.e., Aneurin Bevan, Swansea Bay, Cardiff and Vale, and Cwm Taf)

7.4.2.1 Setting and design

This study will include a cluster, two-arm parallel group, external pilot RCT, with 1:1 allocation, conducted in a secondary care clinic for adolescents with LTCs where consultations take place with patients, parents (if present) and the clinical team member(s). For this pilot RCT protocol, endocrinology young adults' (transitional) clinics have been selected due to the regularity of appointments compared to other conditions. For example, young adult endocrinology clinics at University Hospital

Wales (Cardiff and Vale) take place on a bi-monthly basis, with approximately ten patient appointments per clinic, whereas young adult neurology and renal clinics occur monthly. Furthermore, patients attending young adult endocrinology clinics are more homogeneous, in the sense that the vast majority of patients have type 1 diabetes, which tends to be characterised by preference sensitive options around monitoring glucose levels and balancing carbohydrate consumption with timing, frequency, and means of administration of insulin (453). Patients attending the endocrinology clinics at University Hospital Wales in Cardiff usually move from the paediatric building to the transitional clinic when between 13 to 16 years-old, before transitioning to an adult clinic at approximately 20 years of age. In Wales, under 18s with type 1 diabetes should have *"a minimum of 4 outpatient appointments and HbA1c measurements per year including one annual review appointment, and an additional appointment with a dietitian and a psychologist"* (454). Adolescent patients in Wales who are not newly diagnosed generally attend clinic at least once every three months. In typical appointments, the patient will see the clinic nurse to measure their height, weight, blood pressure and HbA1c, and the annual review also includes a test of eyes, feet, thyroid and kidney function, cholesterol and for coeliac disease. Patients then meet with the consultant and/or specialist nurse to review their blood glucose diary/downloads and discuss optimal blood glucose control through blood glucose testing, carbohydrate counting, insulin dose adjustment and management of exercise, illness, and hypoglycaemia.

The transitional endocrinology clinics will be the units of randomisation (the clusters) for the pilot RCT, and thus, individual participants, from whom the data will be collected will follow the care pathways to which the clinic has been randomised. This clustered design should overcome the problem of contamination between arms. Eligible sites will be located in the four South Wales Health Boards: Aneurin Bevan, Swansea Bay, Cardiff and Vale, and Cwm Taf. Informed consent for clinics to participate will be provided by clinic managers. Consenting participants will follow the care to which their practice is randomised, with identical patient information for both arms providing general information about the study explaining the study procedures. A small sample of patients and parents will be invited to participate in semi-structured interviews, and a focus group will be held with the clinical teams (see Figure 35).

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7.4.2.2 Sample

7.4.2.2.1 Adolescent participant inclusion and exclusion criteria

Potential participants will be identified by a member of the existing clinical care team via patient records. Eligibility criteria will be the same as for participants in Chapters 4 and 6: Living with an LTC for at least a year and between ages 13 to 19. Exclusion criteria include inability to speak English, mental incapacity, or acutely unwell during recruitment.

7.4.2.2.2 Recruitment process

Eligible participants with upcoming appointments at the randomised clinics will be contacted by telephone to be informed of the study and invited to participate. Participants will be informed that their consultation will be audiotaped, and that they will be offered a copy of the transcript if they desire. Identification numbers will be assigned to participants who have consented, and packs will be sent including information sheets and questionnaires testing baseline measures to be completed prior to the appointment. Those who choose not to participate will be asked if they are willing to provide a reason for refusal. Parental consent will be necessary for patients under 16 years to participate, and if the parent(s) are present during the consultation with patients for being audio-recorded (455). The number of known ineligible participants and reasons for ineligibility will be reported. The same will be reported for eligible participants who do not take part.

7.4.2.3 Intervention

Randomisation of clinics will be undertaken by an independent statistician. Clinics (n=4) will be randomised to one of two arms according to computer-generated random numbers stratified by the clinic size (small or large) in the 1:1 ratio. All consenting clinical teams will undergo the implementation training (introductory meeting including SDM training). The participating clinics will then be sent the allocated boxes of booklets. Following assessment of eligibility and completion of written informed consent, participants will be provided a booklet when they next check in at the clinic reception. Participants attending the control clinics will receive usual care with their clinical teams who have undergone the training plus the control booklet. This booklet will have a similar design as the intervention booklet, without the SDM-related content. Participants in the intervention group will also receive care from trained clinical team members plus the "*It's my body, I can have a say booklet*".

Treatment arm allocation as recorded in a randomisation log will be checked against actual treatment received.

7.4.2.4 Outcomes and measures

An effective RCT will describe the differences in outcomes with or without an intervention. The pilot and feasibility study, which a smaller scale version of the full-scale RCT, will need to use the same measures to inform the actual trial. Examples of outcomes can relate to the perceived barriers and facilitators to SDM, as described in Chapter 4, such as knowledge, self-efficacy, social support, and outcome expectations. The full-scale RCT should determine whether these factors change as a result of the intervention. The logic model developed to understand the health problem (Chapter 5, IMA Stage 1) and how the intervention should work to produce change (Chapter 5, IMA Stage 2) can be revisited to develop these questions. The primary aims of the pilot RCT relate to the assessment of feasibility and acceptability, and gather data to plan a future definitive trial, and inform the decision as to how and whether to progress to a full-scale RCT. The main aim of the intervention is to prepare and support adolescents with LTCs to be involved in SDM. This will be the focus of the secondary aims for this study, and primary outcome measures of a full-scale RCT.

7.4.2.4.1 Quantitative outcome measures:

Long-term conditions have been found to a negative impact on quality of life in young people (456). The production of quality-of-life instruments for children and adolescents has continued to accelerate in recent years, although many are condition specific (457-463). The Adolescent Quality of Life Instrument measures generic quality of life in adolescents (aged 12 to 19 years), and has been used to compare those living with and without LTCs (461, 464). This validated instrument's domains, including sense of self, social relationships, environment, and general quality of life, were based upon adolescent interviews and existing assessment instruments (461, 464). Including quality of life as measurement is important, as ultimately quality of life should not suffer at the cost of SDM.

There is no clear guidance around which primary outcome should be used to assess and compare SDM intervention efficacy in paediatrics, and there is a lack of consistency in instruments used (465). It is crucial to be mindful of questionnaire length as it can impact participant response and retention rates (466). Therefore, this

protocol proposes limiting to three outcome measures in addition to the quality-of-life instrument mentioned above. This proposed protocol includes validated, patient-focused measures, which are considered not to be overly onerous, have been used effectively in prior studies with adolescent populations. They measure a range of SDM-related outcomes including decisional conflict, perceived SDM and preferences for involvement.

A review which aimed to evaluate instruments used to assess paediatric SDM interventions reported that the Decisional Conflict Scale was the most commonly used and the only evaluated instrument (465). The Decisional Conflict Scale, which was developed in 1995 to measure a person's perceptions of their uncertainty in making a choice about health care options, measures 5 dimensions of decision-making (feeling uncertain, uninformed, unclear about values, and unsupported; and ineffective decision-making) (73). Secondly, the three-item CollaboRATE scale was developed to measure SDM in the clinical encounter from the patient's perspective (467). CollaboRATE, which has been reported as easily understood and accepted by respondents, involves a 0-9 scale on each item, with higher scores indicating more effort made by HCPs to engage and involve the patient (467). Finally, the Control Preference Scale, which measures willingness to engage in SDM, consists of five statements (468). The statements are categorised into active roles ('*I prefer to make the final decision myself*' or '*I prefer to make the final decision after considering the opinion of my parents*'), collaborative roles ('*I prefer to share the responsibility and make decisions together with my parents*'), or passive roles ('*I prefer that my parents make the decision after considering my opinion*' or '*I prefer that my parents decide on my treatment for me*'). Both CollaboRATE and The Decisional Conflict Scale are brief, validated measures that have been used previously to evaluate the outcomes of SDM interventions aimed at young people with LTCs (117, 208, 306, 469). The Control Preference Scale has also been used previously with adolescent populations (245, 470).

7.4.2.4.2 Process evaluation

The process evaluation will aim to assess implementation of the intervention, mechanisms of impact and consider contextual factors which may influence the intervention delivery. Several methods of data collection (Figure 34) will be used to address th*e following:*

Assessment as to whether the HCPs attended the introductory meeting, participated in role discussions, and received SDM training (dose); and whether participants allocated to the intervention arm received the correct booklet when checking into their appointment, read and completed the booklet (fidelity and reach) will be investigated through qualitative interviewing, observations from recorded consultations and HCP notes. The extent to which participants came into contact with the intervention (reach) will be investigated by gathering the number of participants who completed the intervention arm who received the correct booklet. Acceptability of the intervention and implementation, as well as potential for adaptations will be explored through qualitative interviews with adolescents with LTCs, parents and HCPs. Costs of implementation can be estimated from total pilot expenditures.

Mechanism of impact

Apart from looking at the outcome measures described above, it is also important to investigate intervention effects around potential barriers/facilitators to SDM involvement. To assess mechanisms of impact, qualitative interviews with adolescents will include questions developed around possible determinants of behaviour. A detailed mapping of the adolescent-perceived barriers/facilitators to domains of the TDF was conducted in step 2 of the IMA (see Chapter 5). Key domains included knowledge, emotion, belief about consequences, belief about capabilities, social role and identify, social influences, goals, intentions, optimism and memory, attention, and decision processes (202). The determinants of *Implementation Behaviour Questionnaire* was developed to measure the potential behavioural determinants following the TDF domains (471). Questions relating to the key domains used in developing the booklet can be selected from the questionnaire and adapted to be used in semi-structured interviews with the target audience.

Context

Questions around patients' context and other external factors that may impede or strengthen the effects of the intervention will be included in the interview schedules with adolescents. These will include questions around

condition severity, self-management issues, previous experiences, and the clinical care pathway and administrative processes of the secondary care clinic.
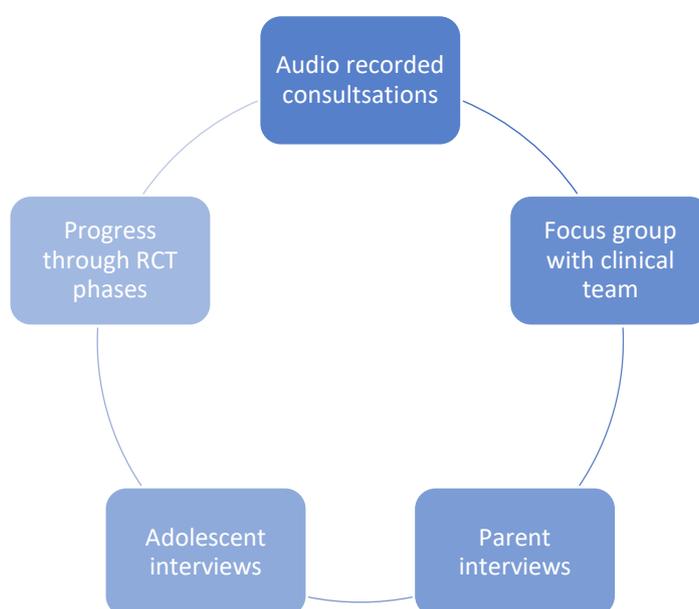
Figure 34. Data inputs to inform process evaluation

As part of the planning process for this study protocol, the stakeholders (including clinical team members, adolescents with LTCs, and parents) will assess the appropriateness of the above outcome measures for the intended patient population and, if necessary, identify alternative or additional measures for key constructs. For example, if it were decided that a measure of objective knowledge should be used, it would need to be condition specific.

7.4.2.4.3 Observations

As an observed measure of SDM, consultations will be audio recorded, and evaluated using a five-Item observation measure based on the three-talk model of SDM (Observer OPTION[5]), which involves rating the efforts made by HCPs within five categories: drawing attention to or confirming the existence of options (option talk); reassurance or reaffirmation of HCP support to inform about and deliberate options with the patient (team talk); checking patient understanding of options (option talk); elicitation of patient preferences in response to the given options (decision talk); and integration of the elicited preferences as decisions are made (decision talk) (100, 472, 473). HCPs are rated from zero (no effort) to four (exemplary effort) on

each item with a total score out of 20. Observer OPTION[5] is a validated and widely used measure, which was modified from the 12-item Observer OPTION[12] by excluding items which were seldom observed or not specific to SDM constructs (472, 474-476). This observation-based measure has been previously used to evaluate SDM with paediatric patients newly diagnosed with LTCs and their families, although the observed SDM predominantly took place between parents and HCPs (474). In this proposed protocol, the focus of the Observer OPTION[5] will be on efforts made by HCPs to involve the adolescents with LTCs in SDM. The observation process can also assist with the assessment of intervention implementation, and evaluation of further SDM training needs, which can be fed back to the clinical teams. In addition, it will allow for discrepancies between observed and reported measures to be identified.

7.4.2.5 Data collection

Participants will complete questionnaires assessing demographic variables (age, LTC, years living with LTC, sex, post code, and ethnic identification) quality of life, and control preference, which will be sent in their packs, prior to receiving the booklet. Copies of the surveys will be available in the clinic if forgotten at home. The allocated booklet will be given once the initial surveys have been completed. The consultation with the consultant and/or specialist nurse will be audiotaped, with a copy offered to the patient and the original retained for analysis. Participants will complete additional questionnaires immediately after the consultation: quality of life and perceived preference again as well as decisional conflict and patient-reported SDM (CollaboRATE) (73, 461, 464, 465, 468). Banu and colleagues (477) reported a dramatic improvement in response rates with the presence of a facilitator and electronic completion of the questionnaire with adolescent participants with type 1 diabetes. Therefore, there will be a member of the research team who is unaware of clinic allocations in the waiting room with the questionnaires available on a tablet device.

Each HCP will record notes including their satisfaction with the decision-making process, and the extent he or she believed the patient's information and involvement preferences were met immediately after the consultation. After the next appointment (approximately 3 months later), participants will complete the outcome measures again. Participants and parents of participants will then be asked for consent to be contacted for a follow-up interview. A member of the study team will contact a sub-

sample of participants and parents in the intervention arm to arrange a convenient time and location for the interview to take place. A purposive sample of adolescents will be attempted for the interviews to achieve an equal number of males/females and distribution of ages. Data collection will continue until category saturation has been achieved (366). Like the participants involved in the qualitative research to inform intervention production (Chapter 4) and pre-testing (Chapter 6) stages, adolescents and parents who participate in the interviews will be offered a £20 voucher. Focus groups with members of the clinical teams will also be held. Figure 35 demonstrates the proposed data collection process.

7.4.2.6 Sample Size

No formal sample size will be calculated for this pilot RCT. An audit of sample sizes for pilot and feasibility trials in the United Kingdom found a median sample size of 30 per intervention arm (478). This is in line with recommendations for pilot trials, so the target will be to achieve at least 30 participants retained in each arm of the trial (60 in total) (479). A review of Pilot RCTs reported a mean attrition rate of 21% (480). Therefore, in an attempt to ensure 30 participants per arm, the aim will be to recruit 40 participants from each allocation: 80 in total. With four participating sites, two in each arm, the aim will be to recruit 20 participants per site. The CONSORT flow diagram (481) will be used to record and report the sampling process (Figure 36). With approximately ten to twenty patients per month attending each site (n=4), and the majority of those likely to be eligible to participate in the study, it could be aimed to complete recruitment by three months.
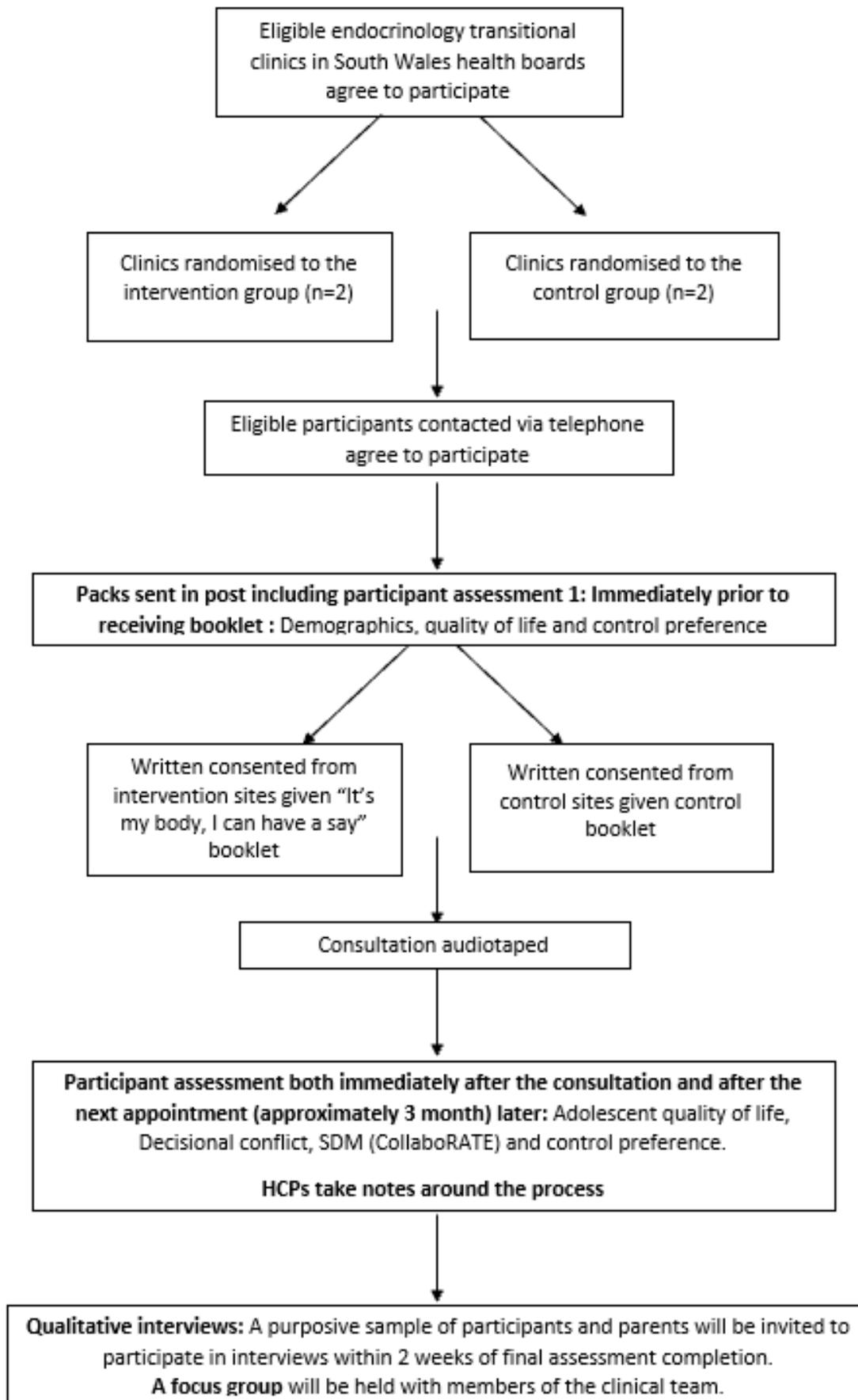
Figure 35. Data collection process
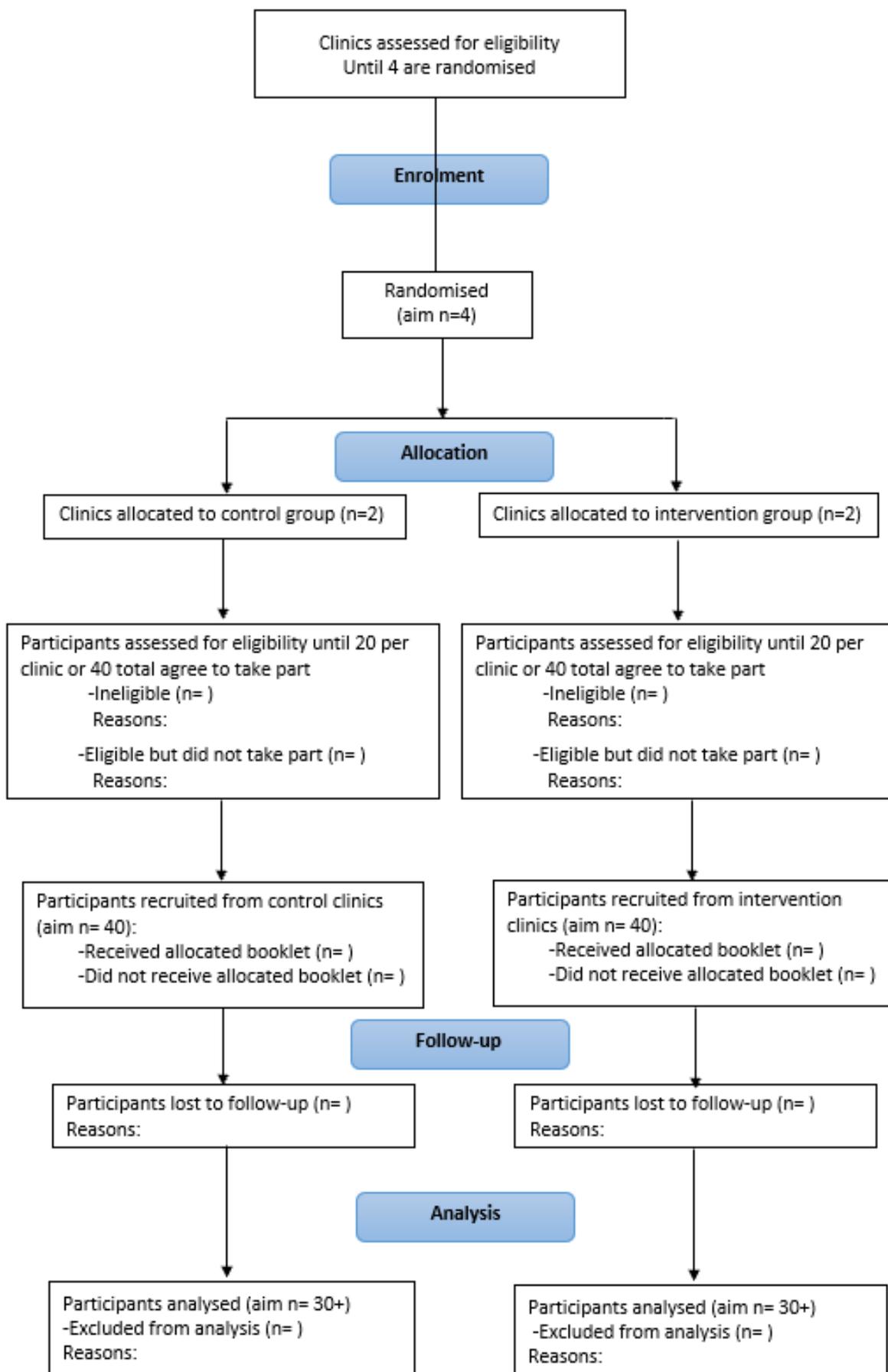
Figure 36. Proposed CONSORT Flow diagram (481) of the progress through the phases of a parallel randomised trial of two groups

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7.4.2.7 Analysis

Demographic data will be analysed using descriptive statistics to determine the characteristics of the sample. The potential effectiveness of the "*It's my body, I can have a say*" booklet will be determined by analysing the differences between the intervention and control group scores on the decisional conflict, reported SDM (CollaboRATE), quality of life, observed SDM (Observed OPTION[5]) and control preference (73, 461, 464, 465, 468) using descriptive statistics.

For the process evaluation, a subset of around ten audio recordings of the consultations with patients who showed the greatest difference in CollaboRATE scores will be further analysed using a discourse analysis method to explore these discrepancies. Discourse analysis examines language production and interpretation of naturally occurring data within a real-life context, with a focus on interaction, and how the speakers attempt to communicate (482, 483). This method, which is well suited to studying complexities of communication within clinical encounters, has been used extensively in research to examine HCP/patient interactions in order to identify how the individuals respond to each other (482, 484-487). A discourse analysis will enable the exploration of potential intervention mechanisms of impact, such how it may affect power dynamics. Recordings of the qualitative interviews with the participants and parents and HCP focus groups will be transcribed and analysed thematically to identify key themes (225).

The results of the process evaluation will be used alongside the pilot RCT results to identify and determine the probable active components of the intervention, including what did and did not work, and changes which need to be made. The knowledge gained from the process evaluation will also be used to help with the interpretation of the pilot RCT results, including fidelity to the protocol and levels of perceived versus observed SDM in both trial arms, which is important to consider alongside the effects. These results will ultimately inform the full-scale RCT, including changes to the intervention and implementation, should it be decided to progress. The feasibility of the study design will be assessed by analysis of the recruitment response, allocation, and study completion rates in combination with the findings from HCP focus groups. The pilot RCT results will be determined through a set of progression criteria relating to the feasibility and process evaluation outcomes.

7.4 2 8 Progression Criteria

To determine whether to progress to a full-scale RCT, with or without adjustments to the recruitment and study process, progression criteria must be met within the allocated three months, allowing for an additional two-month lag (five months total) (Table 35). A literature review of internal pilot RCTs and exploration of key stakeholder's opinions, including triallists, methodologists, statisticians, and funders resulted in the identification of three common issues included in the progression criteria: trial recruitment, protocol adherence and outcome data (488). Due to the inclusion of a process evaluation in this protocol plan, and the importance of the input of the intervention's target audience, I have also included intervention acceptability to the progression criteria.

Table 35. Full-scale RCT progression criteria

Criteria	Green – Go ahead	Amber – Proceed with adjustments	Red – Do not progress
Recruitment (randomisation success)– Percentage of target number of participants recruited within the allotted time	>70% recruitment achieved	40%- 70% recruitment achieved -Discuss potential mitigating strategies	<40% recruitment achieved
Protocol adherence – Receipt of allocated intervention implemented as stipulated in the protocol	<10% failure to receive allocated intervention	10% - 25% failure to receive allocated intervention -Discuss potential mitigating strategies	> 25% failure to receive allocated intervention
Completeness and quality of outcome data Percentage of participants not lost to follow-up	<25% lost to follow up	25%-40% lost to follow up -Discuss potential mitigating strategies	>40% lost to follow up
Acceptability of the intervention Qualitative interviews, particularly as to whether the participant would use the booklet.	Overall High Acceptability of the intervention	Suggestions for improvements –amendments to intervention and/or implementation before progressing	The majority of participants say they would not use

7.5 Discussion

This Chapter describes a proposal for intervention implementation and testing, but stakeholder input will be necessary for both to be coproduced and established. A shared approach where stakeholders and partners participate collaboratively to understand and create strategies can help close the gap between research and practice (439). Findings from this feasibility study with pilot RCT and process evaluation should determine whether progression to a full-scale RCT is justified. If it

is, learning from the study will inform refinement of the intervention, its implementation, and the research methods for a full-scale trial. This testing phase would build on the work conducted in Chapter 6 by exploring the acceptability of the intervention with patients, parents, and HCPs within the clinical environment. Integrating the intervention in routine clinical settings would mean that the results of this stage would be more ecologically valid and will be able to consider a broader range of contextual factors that might influence implementation and/or outcomes of the intervention. Ecological validity refers to the extent to which the findings of the study can be generalized to a real-life setting. Adolescents with LTCs and HCPs provided suggestions for implementation of the booklet (see Chapter 6) but further research may be necessary to assist with the process of effective implementation (169). The think-aloud process and follow up questions described in Chapter 6 focused mainly on intervention acceptability and optimisation with some suggestions for implementation. However, in in hindsight, the pre-testing stage could have placed greater emphasis on collecting data around perceived barriers to, and facilitators for implementation.

From the recommendations from HCPs and adolescents with LTCs which were elicited in pre-testing (Chapter 6), the proposed implementation plan recommends distributing the booklet at the secondary care clinics' receptions when adolescents arrive at their appointments. It could also be beneficial to have the booklet on visible display in the waiting rooms, which has been said to facilitate implementation (443). However, offering written may be seen as a low priority in the duties of clinical staff, or be seen as an inconvenience (489). Furthermore, it has been recommended that interventions to prepare patients for SDM should be distributed to patients before their appointments, but preferably not the same day (96). Adolescents may not have sufficient time to read and process the booklet if only given when they arrive. In the pretesting (Chapter 6) HCPs felt their patients would not have enough time to read the booklet while waiting for their appointment, although adolescents disagreed. However, as explained previously, the health literacy of the adolescents who chose to participate in the focus groups described in Chapter 6 may be higher than the average adolescent with a LTC. For example, adolescents with type 1 diabetes were found to have slightly lower scores than the control group across a number of cognitive domains, including speed of information processing (490). It is important

that the process evaluation contain questions relating to timing and information processing in order to maximise implementation acceptability.

There are logistical issues to sending booklets to patients prior to appointments, which include resourcing of staff and posting charges. Although previously materials could be sent to patients along with appointment letters, new clinic protocols to improve efficiency have resulted in many patients now receiving electronic notification of appointments. In addition, a systematic review evaluating how to best use and evaluate printed patient information materials found that how that distribution methods have an important impact on how they are received by patients and that it is recommended that they be hand delivered (491). HCPs and adolescents both stated that patients would be unlikely to remember to bring the booklet to clinic to complete the sections if it were to be delivered to their homes (Chapter 6).

A process evaluation of pilot testing a booklet aiming to prepare adult patients for SDM reported that participants wanted to have the booklet sent to their homes with appointment letters, as it had been implemented, but also felt the booklet should be available at the place of the appointment (357). This could be another option for implementation of the "*it's my body, I can have a say"* booklet, and if sending paper copies is deemed overly burdensome, the electronic copy could be sent via text or e-mail. Stakeholder discussions would assist with fine tuning the implementation plan prior to initial testing.

To my knowledge, this would be the first trial of a patient-targeted intervention that aims to prepare and support the involvement of adolescents with LTCs in SDM. Drawing on evidence from existing reviews (193, 279), learning from practical implementation challenges (92), underpinned by behavioural change theory (202), and the proposed stakeholder involvement, the "*It's my body, I can have a say*" booklet should be optimised for implementation and testing in secondary care clinics.

The research presented in previous chapters in this thesis highlights the importance of HCP endorsement of adolescent involvement. Paediatric HCPs respond positively to SDM and state it as their preferred form of care (194, 416). However, observed clinical encounters with adolescents with LTCs do not match SDM ideals (270). The observational element of the proposed protocol will enable the appraisal as to whether/what recommendations for further training are necessary. As the

intervention is to be delivered alongside HCP training, it will be difficult to untangle whether the booklet alone has an intervention effect. However, the "*It's my body, I can have a say*" booklet, which aims to prepare and support patients' involvement in SDM, is a complex intervention and must be supported by HCPs in practice to work. SDM preparation needs to be followed by enablement from willing and skilled HCPs, who can reinforce the message that they want patients to become equal partners, as it is difficult to convey this message in a booklet alone.

The booklet delivered on its own would be neglecting considerable barriers to implementation. SDM interventions targeting patients and healthcare professionals together show more promise than those targeting only one or the other (220). Boland and colleagues suggest that knowledge and skills-based training alone are not enough for SDM to be routinely used in paediatric practice, and a more socially supportive environment for SDM is necessary (194). HCPs and SDM experts recommend a team-based approach to SDM training and implementation, which is also more effective if SDM amongst HCPs is to become a routine, normative behaviour (92, 194). The proposal of an introductory team session which provides team-based information and skills-training around SDM based on the team's needs, and enables discussions around individual roles within a team, as well as indicators of success will be a crucial element for the booklet to be implemented successfully.

There is a lack of clear guidance of the selection of instruments to evaluate SDM intervention efficacy in paediatrics, or consistency of instruments used, and researchers are calling for the development of instruments acknowledging the triadic interaction of paediatric decision-making (465). Adolescents with LTCs often say they prefer their parents to play lesser, more supporting role in the decision-making process, however, this is not always the case in reality (204, 239, 279). There is a wide variation between preferences of adolescents with LTCs around decision-making roles, and striving to involve them beyond their preferences can lead to distress, particularly when they do not feel ready (154, 204).

Adolescents with LTCs may not be vocally involved in consultations, and may prefer parents to advocate for them (235). To the observer, it could perhaps appear that the adolescent was not involved in the discussions and/or decision-making, however, discussions with parents could be taking place outside of the clinical encounter, and adolescent views could be accurately represented by their parents. Some of the instruments suggested in the protocol could be inappropriate due to the lack of

consideration of this complex dynamic as they were developed to be used with adults. Another potential issue with the proposed instruments is the possibility of absence of any decision-making in the participants' consultations. The regular clinic appointments aim to review self-management outcomes, but it is possible that often no healthcare adjustments are needed. Therefore, instruments which focus on decision-making (i.e., The Decisional Conflict Scale and CollaboRATE) may be unsuitable for every participant. However, the inclusion of the Control Preference Scale, which aims to measure willingness to engage in SDM; qualitative interviews around the identified determinants to SDM; and the recorded consultations should allow for comparison between groups to provide an indication as to whether the intervention is having any desired effect.

7.5.1 Conclusion

This Chapter proposes a future research plan for the intervention in the form of the booklet titled "*It's my body, I can have a say*" of which the development was discussed in the preceding chapters. This includes proposed plans for implementation and initial testing including a protocol for a pilot RCT and feasibility study with a process evaluation, which could be used to inform the design of a more rigorous effectiveness trial of the modified intervention with a larger sample of adolescents with LTCs. The plans described in this Chapter are purely hypothetical, as they did not fit into the remit of this PhD thesis, but provide a structure of how the tasks could be executed with specific examples. If these tasks were to be undertaken, input from stakeholders, including researchers (e.g., methodological and SDM experts), clinical team members, administrators, adolescents with LTCs, and parents in the process would be vital for every step, and significant amendments could be expected.

Chapter 8: General discussion

8.1 Chapter overview

This Chapter presents an overview and critical reflection of the PhD findings, and highlights the novel contributions of this thesis. The strengths and limitations of the methodological approach throughout the PhD are discussed, and implications for future research, policy, and implementation of shared decision-making (SDM) with adolescents with long-term conditions (LTCs) are considered.

8.2 Summary of thesis findings and contributions

This PhD aimed to (1) understand the barriers and facilitators to SDM with adolescents with LTCs and (2) develop an intervention to prepare and support adolescents with LTCs to be involved in SDM. There were six objectives of this PhD:

(1) understand the preferences and experiences of adolescents with LTCs around involvement in decision-making about their healthcare

(2) identify relevant theory and approaches for intervention development

(3) explore the perceptions of adolescents with LTCs around barriers to, and facilitators for, SDM

(4) develop a theory and evidence-based intervention to prepare and support the participation of adolescents with LTCs in SDM

(5) pre-test the intervention with potential users (adolescents with LTCs) and implementors (HCPs)

(6) propose an implementation plan and a protocol for testing the intervention in order to inform a full scale randomised controlled trial (RCT).

The Medical Research Council (MRC) guidance for the design of complex interventions in healthcare was used as an over-arching framework to guide the work presented in this thesis, specifically, phase one (development) with a detailed proposed plan for phase two (feasibility and piloting) of the framework (169) (Table 36). By following the philosophy of the Person-Based Approach, I was able to develop an understanding of the psychosocial context of intervention target users, and address user experience of the intended behaviour change techniques, which can enhance the use of theory-based and evidence-based approaches to intervention development (200). The findings and contributions of each chapter of the thesis are discussed below (Table 37).

MRC Framework phases 1-2 of 4	PhD Thesis Chapters
Phase 1: Development	
• Identifying the evidence base	Chapter 2 (a systematic review to understand the preferences and experiences of target population) Chapter 4 (A qualitative study to explore the perceptions of the target population around barriers to, and facilitators for target behaviour)
• Identifying or developing theory	Chapter 3 (Identification of relevant theory and approaches for intervention development) Chapter 5 (Selection of appropriate theory aligned with the Intervention Mapping Approach to develop the intervention)
• Modelling process and outcomes	Chapter 6 (Pre-testing of the intervention with target population to optimise acceptability and explore recommendations for implementation)
Phase 2: Feasibility and piloting • Testing procedures • Estimating recruitment and retention • Determining sample size	Proposed in Chapter 7 (A plan for a protocol of feasibility, pilot testing and process evaluation of the intervention)

Objectives 1 to 3 (Chapters 2 to 4) contribute to the first aim of the PhD. Chapter 2 presented a mixed methods systematic review of 27 studies that synthesised the preferences and experiences of adolescents with LTCs around being involved in decision-making about their healthcare (Chapter 2). This review, published in 2018 (204), is currently the only systematic review, to my knowledge, which aimed to synthesise adolescents' perspectives alone. Two other reviews (one published before, one after) have also looked at SDM in paediatrics, however they predominantly included studies reporting parent and HCP generated data, with patient reports often difficult to disentangle (114, 193). Furthermore, my review focused specifically on the narratives of adolescents with LTCs, who are likely to have different perspectives and needs to children in general.

Findings from the review include varying preferences for involvement, which would often depend on the seriousness of the decision (i.e., adolescents prefer to be more involved in "small" decisions as opposed to "big" decisions); acute wellness, readiness, or age, if under 11 years. Adolescents with LTCs generally feel they should be able to choose the extent of their involvement; however, they often see parents and HCPs as having this control, and express a need for adult support and encouragement in order to be involved. Adolescents with LTCs see parents and

HCPs as gatekeepers of information about their conditions and healthcare options, and believe that sharing the information about their health should be a normal thing to do. When adolescents received sufficient information, they reported benefits such as feeling less anxious and more prepared and capable of following through with decisions around healthcare options. However, adolescents often reported a lack of information and being left out of discussions, which makes them feel as though they cannot, or should not be involved. When preferences for involvement go unmet, adolescents with LTCs report feelings of fear, frustration, and exclusion.

The influence of decisional factors, power relations, emotional state and information provision on paediatric decision-making is consistent with other researchers' findings (193). However, the review reported in this thesis provides a more in-depth depiction of the adolescents' preferences and experiences including the variation, and mismatch, between the two. The review was helpful for identifying factors which may influence preferences for involvement, and what may contribute to positive or negative experiences with healthcare decision-making. I concluded that further exploration around perceptions of barriers and facilitators to SDM was necessary, including a focus on reasons for the identified mismatch between preferences and experiences.

The next Chapter (Chapter 3) aimed to address thesis Objective 2. Seven theoretical models and four intervention development frameworks and approaches were outlined, and their use in relevant previous research investigated. I found that the majority of the models were not sufficiently effective in explaining the behaviour of interest, as they were lacking important constructs identified from the literature discussed in the preceding chapters which would be likely to account for adolescent involvement (or lack thereof) in SDM. These include failure to adequately consider potentially important factors for determining the target behaviour such as self-efficacy (e.g. Health Belief Model (294)), emotion (e.g. Theory of Planned Behaviour(295)), social norms (e.g. Health Belief Model(294)), individual traits (e.g. Social Cognitive Theory (297)) or contextual factors (information-Motivation Behavioural Skills Model (299)); as well as limited evidence for effectiveness (Self-determination theory (300)) or ability to predict actual behaviour (i.e. the intention-behaviour gap).

It was therefore decided that a theoretical model or framework would be selected following further research into the target behaviour. This would enable the selection of the most appropriate option upon gaining more in-depth information about the behaviour from the perspective of the target population. In line with this decision, I decided the Intervention Mapping Approach (IMA) would be the most suitable approach for intervention development in this context. The IMA involves first identifying the behavioural and environmental determinants related to the target behaviour and then selecting of the most appropriate theoretical methods (201).This aligns with the Person Based Approach, where potential intervention users are at the centre of intervention development (200). These complementary approaches provided a structure for subsequent chapters.

A qualitative exploration of perceptions of adolescents with LTCs around barriers to, and facilitators for SDM using participatory interviews addressed Objective 3 (Chapter 4). Findings were used to corroborate those of the systematic review, and to gain in-depth insight into the perceptions around barriers and facilitators to SDM in order to inform the intervention development. This study sought to fill the gaps in the literature identified by the systematic review. Firstly, due to a lack of literature around SDM in adolescent populations, the focus of the review was experiences of healthcare decision-making in general. This qualitative study therefore aimed to look particularly at participation, or the lack thereof, in SDM, including what adolescents with LTC perceived may motivate or hinder involvement. Secondly, findings from the systematic review revealed a mismatch between adolescent preferences and experiences around decision-making, little explanation could be found for this mismatch. Preferences for, and experiences of involvement were therefore elicited during the interviews, and any discrepancies were further explored to identify possible reasons. This was done using the pie charts, which had been used previously to look at preferences and experiences around involvement in an adolescent population, although the pervious authors did not report reasons for discrepancies between the two (239).

This qualitative study was useful for identifying barriers to, and facilitators for SDM. Findings consistent with the systematic review included themes around power imbalance, self-efficacy, social norms and support, outcome expectations, and readiness. Similar findings have also been reported in adult populations and general

paediatrics (193, 256). Additional contributions from this specific population included disengagement from discussions due to perceived lack on control, or an attempt to restore a normalised self-image despite living with a LTC; and sharing positive SDM experiences with others as a facilitator.

The following three Objectives (4, 5 and 6) relate to the second aim of the PhD. In the qualitative interviews (Chapter 4), adolescents with LTCs provided insight into acceptable intervention format, delivery, design, and content. Step-by-step intervention development was described in Chapter 5 using the IMA with the Theoretical Domains Framework (TDF), which, due to the findings from previous chapters, was determined to be the most appropriate approach to account for the behaviour of interest (202).

The intervention mapping resulted in development of a twelve-page booklet titled "*It's my body, I can have a say*". Sections of the booklet, which aimed to facilitate involvement and tackle barriers identified by adolescents, state benefits to SDM, including positive outcomes; explain how to become more involved, including activities to facilitate involvement; respond to common questions and concerns; provide stories of involvement of other adolescents with LTCs; and offer a section for parents. Original quotations obtained from the qualitative study described in Chapter 4 were included.

To my knowledge, and through investigation of the Ottawa Hospital Inventory of Patient Decision Aids and SDM tools (112), the "*It's my body, I can have a say*" booklet is the only theory and evidenced-based intervention targeted at adolescents with various LTCs aiming to prepare and support them to participate in SDM with HCPs about whichever relevant healthcare decisions, attempting to address perceived barriers and facilitators. Other interventions to improve SDM targeted at adolescents with specific, more prevalent conditions, including juvenile idiopathic arthritis, (117, 268, 492) asthma (164, 206, 209) and Type 1 diabetes (233, 280, 493) exist, although some lack either lack theoretical underpinning (117, 207, 208, 233, 268, 280, 493) or patient involvement in the development (208, 233, 280, 492). These interventions have the advantage of being tailored to condition-specific needs, including specified questions and detailed information about options, symptoms, and complications. However, developing an intervention for every adolescent LTC would

be logistically impossible, particularly for the rarer conditions. Early in the research process (Chapter 1) parallels were drawn between adolescents' experiences across LTCs, which were confirmed in Chapters 2 and 4. Although a generic intervention cannot cater to the specific needs as with the other intervention examples, the booklet provides adolescents with prompts for this information to be sought from members of their clinical team so that individual details can be provided. In addition, many of the interventions outlined above focus on the decision-making process as the decision is introduced and occurs with the "preparation" nature. *"It's my body, I can have a say"* attempts to prepare adolescents with LTCs to participate as and when decisions arise as well as support them through the process.

Chapter 6 describes the booklet pre-testing using the think-aloud technique (203) with focus groups of adolescents with LTCs and HCPs (Objective 5). Overall, the booklet was well received; adolescents liked the layout and design, and found the content to be personally relevant, which could be tailored to their specific needs. The pre-testing confirmed that the booklet had potential to be effective in addressing the identified barriers to SDM. This included social support and encouragement (e.g., HCPs want them to be involved); facilitating the decision-making process by breaking it down and providing question prompts; addressing concerns around making the "*wrong"* decision or saying something "*stupid*"; increasing self-efficacy; gaining awareness of others experiencing similar circumstances; and benefits of involvement.

The booklet was also described by HCPs as a useful tool to help them promote SDM and gain insight into preferences of their patients; remind patients they can see HCPs alone; and encourage parents to support their child's involvement. Some potential problems with the booklet were identified. These included accessibility of the booklet, particularly for those with learning difficulties; appropriateness of the language used, such as the use of the word *"teenager"*, which could be seen as pejorative and "*doctors and nurses*" which is not inclusive of the entire clinical team members; and the failure to draw attention to the fact that adolescents were involved in the booklet's development.

The final thesis objective involved implementation mapping and developing a proposed protocol for initial testing of the booklet. Both HCPs and adolescents with

LTCs suggested that the booklet should be distributed at reception in the secondary care clinics when patients check in for their appointments. Chapter 7 provides a template for further research beyond the remit of the PhD. The importance of stakeholder involvement to undertake these processes is emphasised, as well as HCP training, and discussions around role allocations to facilitate implementation.

Table 37. Thesis Chapter findings and contributions

Chapter	Study design	Primary Aims	Findings and novel contributions
2	Systematic Review	Explore the experiences and preferences of adolescents with LTCs around being involved in healthcare decision-making	• Most adolescents with LTCs want to, and feel they should, be involved in decision-making about their healthcare, and able to choose their level of involvement. • Decision-making preferences vary between and within individuals, with adolescents aged 11 and under and those feeling acutely ill preferring less involvement. Preferences often depend on the nature of the decision. • Adolescents (i.e., parents and HCPs) look to adults (i.e., parents and HCPs) to support their involvement. • Decision-making preferences are often not met, which has negative emotional consequences. The review highlights the needs for further research to explore reasons for the mismatch between preferences and experiences
3	Scoping reviews	Evaluate relevant theory in the context of SDM involvement of adolescents with LTCs alongside approaches for intervention development	• Most of the popular behavioural theories are missing important constructs relating to adolescents' 'involvement in SDM, for example emotion. In absence of an effective theoretical model to explain the target behaviour, the TDF, which includes comprehensive coverage of possible behavioural influences, was identified as relevant for this context. • Due to the shortage of pre-existing literature around involvement of adolescents with LTCs in SDM, the IMA was decided to be the most appropriate approach to intervention development as it involves investigation of barriers/facilitators around the target behaviour prior to the selection of theory.
4	Qualitative individual interviews	Identify the perceptions of adolescents with LTCs around barriers and facilitators to SDM	• Adolescents with LTCs see adults as having authority over the decision-making process, although they would generally prefer parents to have a smaller, more supportive role. Adolescents often report insufficient information provision from HCPs. • Adolescents need to feel that SDM involvement aligns with their sense of self, dissonance can lead to avoidance around their condition including discussions. • Adolescents need to see SDM as beneficial to them
5	Intervention development	Describe the systematic development of an intervention to prepare and support the involvement of adolescents with LTCs in SDM	• The IMA, TDF, and adolescent suggestions were used to develop a 12-page booklet in attempt to address perceived barriers and facilitators to SDM • Key elements of the booklet include benefits of involvement, how to be involved, tools for weighing up options, answers to questions and concerns, real patient quotes and stories, and a parents' section.
6	Qualitative individual interviews and focus groups	Pre-test the intervention for acceptability, and suggestions for improvement and implementation	• Adolescents with LTCs and HCPs reacted positively to the booklet, but suggested changes to improve acceptability such as more user-friendly language, multimedia access, and drawing attention to the fact adolescents were involved in the development. • The booklet was seen to potentially address the barriers to SDM by enabling increased knowledge and awareness of how to be involved; self-efficacy around decision-making; perceived reassurance and support from HCPs; relating to others' experiences; and perceived control over, and benefits of, involvement.
7	Implementation Plan and Protocol for a feasibility, pilot RCT and process evaluation	Develop a preliminary implementation plan and propose a protocol to assess the acceptability of the intervention and implementation in a real-life setting including adaptation, and to inform the undertaking of a full scale RCT	• Implementation plan includes an introductory meeting with SDM training and discussions around implementation roles. The booklet is suggested to be distributed at reception when patients check in for appointments. • The proposed plan for a feasibility study with pilot RCT and process evaluation aims to recruit 80 participants from a young adult endocrinology clinic to either the control group (booklet) or usual care. Evidence from existing reviews, learning from practical SDM implementation challenges and, behavioural change theory was used to develop an exemplary protocol for testing in a real-life setting was outlined, although further consultation with stakeholders will be necessary for finalisation.

8.3 Key Discussion points

Collectively, my thesis findings suggested that many diverse factors influence SDM involvement in adolescent LTC care, and that the research has led to the development of an intervention which can potentially prepare adolescents for, and support their involvement in, SDM as the main unique contribution to the field of SDM with adolescents with LTCs. However, further efforts are still necessary to assess and implement the "*It's my body, I can have a say*" booklet.

A model for SDM with adolescents with LTCs has also been developed as a result of the thesis findings (Figure 37).
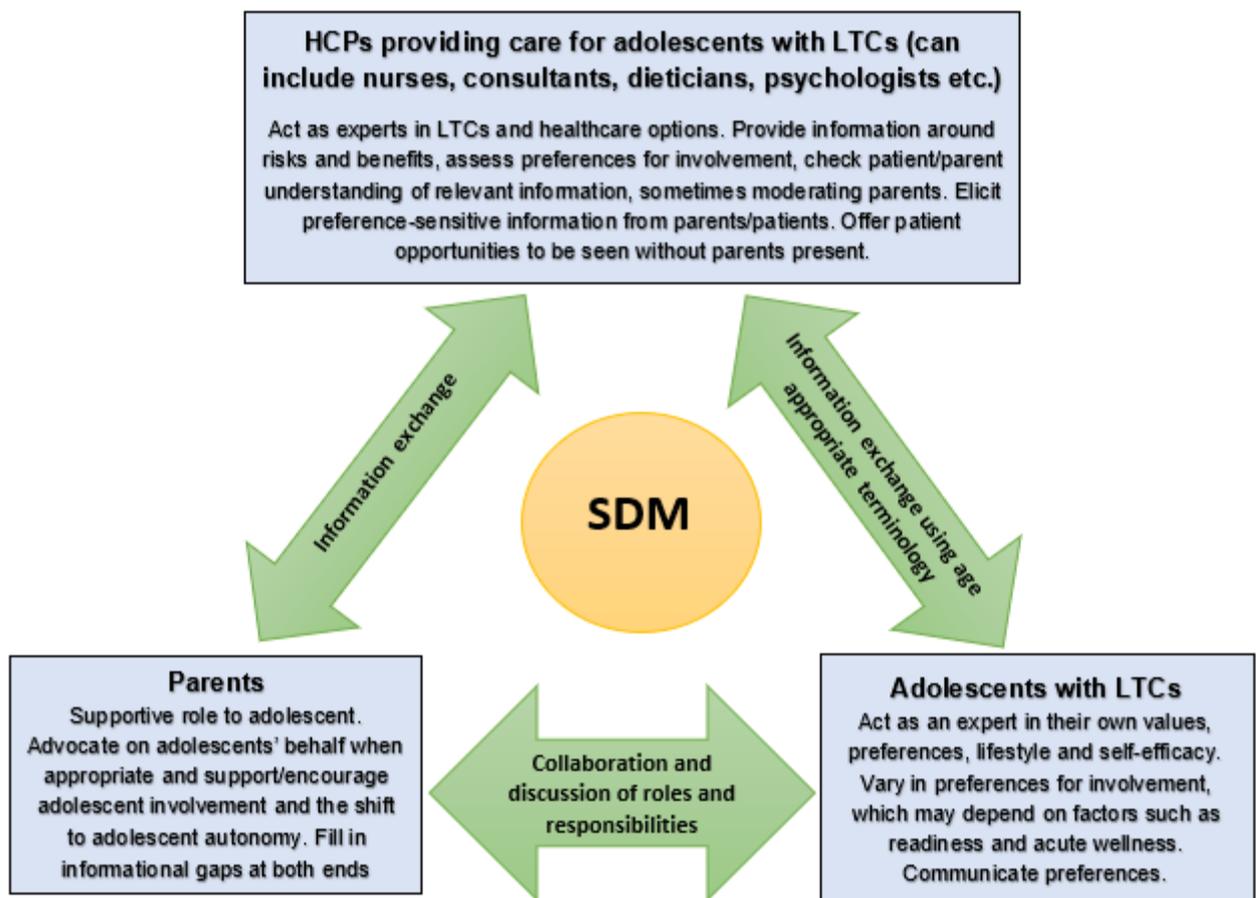
Figure 37. Model of SDM with adolescents with LTCs

The findings from this thesis lead to three broader discussion points: the importance of 'real' empowerment and enablement, making SDM the norm for adolescents with LTCs, and a need for a holistic approach to promoting an effective partnership.

8.3.1 "*I can have a say*" – The importance of 'real' empowerment and enablement

A consistent theme running throughout this PhD thesis is the importance of adolescent empowerment. The patient-HCP power imbalance has been frequently reported as a significant barrier to SDM (145, 256). This imbalance may be even more pronounced in younger populations due to their position in society, and the presence of parents whose consent they often must rely on (e.g. to undergo treatment or participate in research) (52, 56) .

Strides are being made internationally to empower adolescents; The UN Convention on the Rights of the Child, which recently celebrated its 30th anniversary, has enabled more young people to have their voices heard and participate in their societies (494). The UK Government is in the process of developing the New Youth Charter, which strives to empower young people and give a voice about issues which concern them (495).

Adolescents with LTCs express a desire to have more a say in the decision-making about their healthcare, and have their voices respected and listened to. This includes decision-making around transition to adult care, service delivery, healthcare option preferences, and preferences for participation (382, 496-498). Solely providing patients with information about options (e.g., a decision aid) is not sufficient to incite involvement. Patients need to be prepared to take part, which can involve changing attitudes around involvement, including awareness that their expertise is as important as that of the HCPs (96). Preparation is then followed by enablement, which involves providing knowledge and assisting patients to clarify values (96).

The *'It's my body, I can have a say'* booklet, which was developed to prepare and support adolescents' involvement in SDM, includes statements of empowerment (e.g., "*You are the expert on you and your life*"), and attempts to initiate enablement with prompts to instigate information gathering and values consideration.

Adolescents with LTC need to be aware of their own expertise and feel capable of making a "*good*" decision for them. Several of the theoretical constructs discussed in Chapter 3 emphasise the importance of self-efficacy for a desired behaviour to take place (295, 297, 299-301). As well as feeling capable of involvement in healthcare decision-making, adolescents also need to feel confident that they can follow through

with the chosen healthcare option(s). Self-efficacy around the ability to engage in healthcare options (i.e., adherence to self-management regimes) has been found to be related to numerous benefits for adolescents with LTCs such as: improved health and emotional outcomes, better adaption to the LTC, better quality of life, and increased readiness for transition (47, 499-505). An intervention which aims to support and empower its users should therefore include attempts to improve self-efficacy around self-management.

It is crucial that strides for adolescent empowerment are not only symbolic but are met with willingness from others for adolescents to actually have control. HCPs providing care for adolescents with LTCs need to create an environment where patients feel they can have a say, and are not seen to be pushing their own agenda. Although most HCPs state SDM as their preferred role in a medical encounter, many revert to paternalism in practice (416). HCPs have been observed to provide more detailed information about their preferred option with minimal details of other options, and often fail to elicit adolescents' preferences (270). While it is likely HCPs see this as acting in adolescents' best interests, it does not meet SDM ideals, and may not result in selecting the best option for the individual patient.

Previous chapters in this thesis reported that when attempts to be involved go unmet, adolescents can suffer emotional consequences (Chapter 2), and that a perceived lack of control can cause complete disengagement from the decision-making process (Chapter 4). This may result in having no say over the decision, or taking complete decisional control, which can be detrimental to the health of the individual without the input of HCPs. For example, one of my participants, Stephanie, a 15-year-old with epilepsy, described how she decided to stop taking her medication in order to gain some control, and consequently suffered more frequent and severe seizures.

The Children's Society's "*Good Childhood Report 2019"* states that the majority of adolescents feel as though their views and concerns are not listened to and taken into account, which has a negative effect on their wellbeing (506). The report advocates for "*any approach that gives them [young people] a chance to have their say and make their mark*" (506). Adolescent involvement needs to be seen as meaningful, that they have a real element of control as participation if not done

properly can be met with criticism (507). As Chapter 2 reports, involvement which is perceived as tokenistic can lead adolescents to believe their contribution is not valued. Adolescents with LTCs want to be involved if it is done properly, if it is about issues directly affecting them and if they see involvement as likely to yield results that will benefit them (508). This means that discussions around SDM participation and related expectations, including roles, need to be open, purposeful, and ongoing.

8.3.2 *"I don't want to be different"* – Making SDM the norm for adolescents with long-term conditions

In line with the findings reported in the chapters of this thesis, qualitative studies exploring the perspectives of adolescents with various LTCs have consistently found that being 'normal' and not treated differently from peers is of great importance to the individual (17, 330, 493, 509-513). Many of the theoretical models discussed in Chapter 3 include the construct of social influence, including normative beliefs, as a key determinant of health behaviour (295, 296, 300). Adolescents' endeavours to be 'normal' while living with a LTC can have a critical effect on self-management if they feel their condition differentiates them (514). LTCs can have a significant impact on adolescents' identity and their ability to connect with others (509).

In pre-testing of "*It's my body, I can have a say*", participants often commented that the booklet had the potential to make adolescents with LTCs "*feel less alone*" as they could relate to the patients' stories, and it raised awareness around the prevalence of various LTCs. Meet up groups run by charitable organisations, such as Diabetes UK Cymru, Kidney Wales and Valley and Vale Community Arts, provide adolescents with the opportunity to socialise with others living with LTCs, to share stories and experiences without feeling set apart as a result of their condition. Gareth, an 18-year-old with a renal condition, described how attending the groups could enable individuals to share successes of involvement in discussions and decision-making, which can be encouraging and may increase the sense of normative behaviour (Chapter 4).

However, many adolescents with LTCs I encountered during this project were not aware of, or afforded the opportunity of, having such groups available to them. The paediatric and young adults' nephrology and endocrinology clinics at some regional hospitals employ youth workers who interact with the adolescents in the clinic waiting

rooms and invite them to regular organised events. Two adolescents attending these clinics stressed the importance of the arranged meet up groups to interact with others in similar situations, which made them feel like normal adolescents. The neurology and rheumatology clinics did not have the same support available. I interviewed two female participants with epilepsy, both 16 years of age from the same small town attending the same secondary care clinic, however, each mentioned they had never met anyone their age with epilepsy. When adolescents with LTCs do not know anyone their age with the same condition, they can find coping with the condition more difficult as a result (515).

Being treated as normally as possible within the family can help adolescents to develop the personal skills needed to cope with the challenges of reaching adulthood with a LTC (516). Adolescents with LTCs try to see themselves as 'normal' individuals, but their strategy for normalisation can vary (517). It has been argued that they may be more likely to engage in risk behaviour in order to demonstrate their 'normality' and be accepted by their healthier peers (14, 518). Attempts to attain and/or maintain elements of a normal life can have a strong influence on adolescents' healthcare decision-making, for example rejecting medical interventions to maintain independence from technology, or selecting options which facilitate increased social participation (519). This strengthens the argument for understanding adolescent priorities in decision-making in order to enable the selection of the best option(s) for the adolescent's quality of life, in line with their sense of normality.

8.3.3 *"It takes three"* – The need for a holistic approach to promoting an effective partnership

Adolescents with LTCs should be acknowledged as partners in decision-making, with adolescent participation becoming embedded as an integral part of their encounters with HCPs (496, 520, 521). SDM has achieved high policy prominence but adoption into clinical practice remains slow, and HCPs' attitudes are a commonly reported barrier to implementation (92, 113, 193, 440). Fortunately, HCPs' attitudes towards SDM appear to be improving, and willingness to use this approach seems to be increasing in more recent cohorts of HCPs (440, 441). Embedding SDM training into medical curricula may be an effective solution for barriers to widespread

adoption of SDM, which has been found to have a positive effect on medical students' SDM skills and confidence (441).

Research in this thesis (Chapters 2 and 4) and previous literature demonstrate how professional attitudes and behaviours can either facilitate or hamper the participation of adolescents with LTCs in SDM (142, 143, 150). The "*It's my body, I can have a say*" booklet is unlikely to be successful as a standalone intervention, and could be potentially damaging, if adolescents' efforts to be involved in SDM are not supported by members of their clinical teams. When considering implementation, it was clear that the booklet needs to be delivered alongside other interventions, particularly HCP training. Many HCPs delivering care to adolescents report receiving insufficient training in communication skills with this population (522-524). Adolescents with LTCs rate HCP interpersonal factors as most important to their judgment of quality of care, and generally prefer HCPs to communicate directly with them rather than with their parents (525). Joos and colleagues suggest that interventions to improve HCP-patient communication may be ineffective if both parties are not involved (526). Chapter 7 describes an implementation plan, including a proposal for tailored HCP training prior to implementation.

Training should include how to adopt interaction skills which aim to build rapport and reduce power imbalance in order to develop trust with adolescent patients, which are prerequisites of shared responsibility for treatment (527). Age-appropriate communication skills should include honesty and openness; asking direct questions; maintaining confidentiality; and discussing psychosocial and option-related subjects relevant to adolescents with LTCs (524, 525, 528-530). In addition to improving the likelihood of SDM taking place, effective communication with adolescents with LTCs has the potential to improve adherence with the treatment regimens, wellbeing, and LTC outcomes (524). Learning how to effectively communicate openly and honestly with, and elicit preference from adolescent patients, enables a shared understanding of what is most important to the adolescent. HCPs often lack the ability to judge what might appeal to adolescents when communicating about risk behaviour (531). Furthermore, HCPs may spend too little attention to issues which are important to adolescents with LTCs (531). During intervention pre-testing (Chapter 6), some HCPs commented that the booklet would be useful for helping communication with

patients by eliciting values and preferences, enabling HCPs to learn more about their patients

Chapter 4 describes how HCPs' communication approach can act as a barrier or facilitator to SDM. Sam and Sophie described feelings of dread towards attending appointments where they felt they might be reprimanded if their 'numbers' were sub-optimal. This was reinforced in Chapter 6; a diabetes transition worker clarified that patients' experiences of anxiety around blood results was a common issue. These experiences can intensify the power imbalance, making it difficult for adolescents with LTCs to instigate discussions around important issues, thus reducing the likelihood of SDM. What may be seen by HCPs as non-compliance with healthcare recommendations may represent efforts to balance the demands of being adolescents with those associated with their LTC demands (386).

Adolescents with LTCs are often reluctant to ask questions that may reveal poor adherence to treatment plans, or ask questions around behaviours they think will be disapproved of, such drinking alcohol or taking part in activities deemed as risky such as extreme fairground rides (382). This is often because they do not want to be reprimanded, or told about restrictions to their lifestyle (382). One of my HCP participants stated he would not encourage patients to discuss issues around behaviour in which they should not engage, such as drinking and drugs (Chapter 6). However, as Lisa (participant aged 16 with epilepsy) articulated, it is important for these conversations to take place, as otherwise adolescents will look to other, potentially less reliable, sources for information (Chapter 4). As mentioned in Chapter 1, adolescents with LTCs may be even more likely to engage in risk behaviours than those without (14). Open, non-judgemental communication with HCPs can help adolescents face their challenges and realise their strengths and options (386). Adolescents with LTCs need to be reminded that they can see HCPs alone to discuss certain issues which, as noted in Chapter 6, is something HCPs often forget to do. Van Staa (528) advocates for adolescents with LTCs to be seen alone for a portion of the consultations as routine practice. This not only allows for confidential discussions of sensitive topics, but also enables to adolescents to gain experience of consulting with HCPs alone, which may become a necessity if moving away to attend university or work.

HCPs should not only consider the presence of parents in the room during clinical encounters, but also student doctors. At regional teaching hospitals, student doctors are often invited to sit in on consultations, which can significantly inhibit communication between adolescents with LTCs and members of their clinical team (382). This issue was also brought up by Lisa, who described the presence of too many adults in the room as overwhelming, and felt it prevented her from raising concerns, and caused confusion around who she should address. Where the adults are often seen as authoritative figures, adolescents need to feel as though they have control over who is, and who is not, present during their consultations.

Parents, HCPs, and adolescents with LTCs generally have shared goals, which include improved health and overall quality of life. Strides towards a working partnership to achieve these goals should include the establishment of preferred roles. Findings from Chapters 2 and 4 confirm that adolescents generally want their parents to be involved in healthcare decision-making, but often prefer them to have a lesser role. Adolescents with LTCs look to parents for confirmation of their capability to be involved decision-making, which enables the perception of themselves as experts (532).

Parents play an important role in supporting adolescents' involvement in decision-makings by attempting to include them in discussions, deliberating options and advocating on their behalf when adolescents feel they are not able to participate (154, 155). Adolescents with LTCs often view parents as their champions, representing their views, looking out for their best interests, and encouraging their participation, which facilitates involvement (154, 155). Parental support can increase adolescents' self-efficacy around involvement in SDM as well as condition management (51, 238, 418). Parents help adolescents with LTCs to acquire self-management skills and to gradually gain independence, taking ownership and responsibility for their condition management (44-46). Collaboration between parents and adolescents in healthcare decision-making can facilitate the integration of the deliberated option into the family routine, thus increasing the likelihood of adherence to the healthcare regime (156-158).

However, adolescents with LTCs sometimes feel that parents interfere with their daily regimens due to concerns, often to the frustration of the adolescents (48).

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Furthermore, parents often have less confidence in their child's capability to take responsibility over their healthcare than the adolescents themselves (48). Adolescents with LTCs can feel hindered by their parents' concerns, which affirm feelings of being different (533). Chapters 2 and 4 report how parents sometimes take over during consultations, blocking adolescents attempts at involvement in decision-making by interrupting and answering questions in their place. However, research has shown that parents are not always reliable proxies for their children's views (48, 162, 226, 229, 230, 232, 240, 534). Parents may weigh the impact of living with a LTC more heavily than the adolescent, one example includes perceiving more limitations on social relationships (534).

Parents often report difficulties striking a balance between controlling and letting go, and may need support with this process (46, 48, 49, 51). Parents of adolescents with LTCs fear of the (potentially life threatening) consequences of failure to manage the condition effectively, and would like more assistance from HCPs with the process of increasing their child's independence and equipping them with the skills to make healthcare decisions (49, 50). Parents play an important role in helping adolescents to develop independence but may need help to understand how best to support adolescents' acquisition of autonomy (44-46). '*Skills for Growing up'* is an example of a tool used with families in the Netherlands to promote the independence of adolescents with LTCs, such as epilepsy and kidney disease, involving a collaborative approach to decision-making, goal setting and self-management, and supports healthy growth into adulthood by providing a list of basic age-appropriate skills and competences (533, 535). Although the tool can be somewhat confronting for parents, it was found to facilitate communication development and adolescent empowerment (533).

8.4 Implications for policy and practice

8.4.1 A standardised but individualised approach to long-term healthcare delivery

Over thirty years ago, Stein and Jessop argued for a non-categorical approach to long-term paediatric care delivery stating that "*a non-categorical approach has the potential for empowering health care practitioners by allowing them to begin to understand what is necessary for complete care of a given child with sickle cell*

anaemia, for example, but also prior experiences with children with other chronic conditions such as asthma or diabetes" (15). The basis of this approach is the notion that young people growing up with different LTCs face similar adaptive challenges regardless of type of condition. In this respect, adolescents within a given diagnostic group may vary as much as between different diagnostic groups.

More recently, Newbould and colleagues drew parallels between experiences of adolescents with asthma and diabetes, suggesting that their research findings around condition responsibilities and roles would be relevant to young people with other chronic conditions (28). As reported in chapters 2 and 4, involvement preferences tend to be more decision-specific than condition-specific. The current discrepancy in service provision, such as access to organised events, sees adolescents receiving insufficient psychological and social support based on their condition.

However, one size does not fit all, for example not all adolescents with LTCs want to meet other patients (528). Adolescents with LTCs emphasise the importance of individualised care (386). The variability of preferences within and between adolescents with LTCs, as reported in the systematic review (Chapter 2), emphasises the need for a flexible and tailored approach to care delivery. This was reiterated in the pre-testing described in Chapter 6 in which users praised the personalised and individually relevant nature of the intervention. A realist approach needs to be adopted, which asks "'*what works for whom in what circumstances*?" (536).

As an example, the lack of individualised approach to transition to adult care seems to be comparable across diagnoses, adolescents commonly report feelings of not belonging and being redundant during the process (528). As with their treatment decision-making, adolescents need to be acknowledged as competent collaborators in their own transition, at which point SDM is crucial and may protect adolescents from additional health problems at this vulnerable stage (496). Individual differences affect adolescents' readiness to transfer (505, 537). Adolescents want to be a part of the process, appealing for HCPs to listen to their sensitive needs, which are often different from others attending the same facility (537). Ways to improve and individualise the transition process include discussions around expectations, joint

planning of the steps involved, meeting the new team beforehand and ensuring the adolescent has the necessary knowledge and skills beforehand (521, 528, 538).

8.4.2 Adolescent involvement in service and intervention development

Adolescents with LTCs, as frequent and longstanding users of health services, have a lot to offer to inform service development. A survey of all health authorities and NHS Trusts in England identified 29 initiatives involving young people with LTCs in consultations regarding service development, showing that involvement is possible, and can have a positive impact on services (539). Benefits of involving adolescents with LTCs in service design include developing confidence, providing the opportunity to voice concerns and increased uptake of services (540).

One strength of the '*It's my body, I can have a say'* intervention was the co-production element, including suggestions for format, delivery, design, and content as well as feedback on the booklet prototype. Apart from improving adolescent-friendliness, it was said that adolescents' involvement in the development increased the desire to engage with the booklet. Several HCPs compared the content of "*It's my body, I can have a say*" to "*Ready Steady Go"* in the pre-testing interviews (Chapter 6). "*Ready Steady Go"* is distributed to adolescents across the paediatric secondary care clinics to support transition. Formalised feedback reported that "*Ready Steady Go"* helps address the key issues for a good transition to adult services and improves clinical practice (541). However, according to HCPs, drawbacks include being overly long and formal, and it was noted that the fact adolescents were not involved in the development made "*Ready Steady Go"* less user-friendly. This missed opportunity could limit the intervention's attractiveness to the target population, thus hindering the effectiveness of the intervention.

Lightfoot and Sloper (539) created guidelines to assist NHS staff to support the involvement of young people, particularly those with LTCs, in local decisions about NHS services development. The guidelines provide information about the consultation process, methods for involving young people, training needs and how to provide feedback (539). Adolescents with LTCs report personal benefits to involvement in NHS service development including: a chance to make a difference, feeling valued/respected, learning to take responsibility, and forming relationships

with others (507). The process of working with others could be particularly beneficial to individuals, as adolescents with LTCs tend to have less social participation (542).

However, it is essential that results of their involvement are evident to adolescents. Tangible outcomes are important as evidence that they have been listened to and taken seriously (507). Complete co-production with adolescents is complicated and challenging to execute. Sligo and colleagues' (509) attempt to collaborate with adolescents with LTCs as co-researchers was unable to fulfil the co-production they had planned, as the co-researchers were very busy and lacking experience and skills to administer in-depth interviews. They also found it to be ethically difficult to collaborate with inexperienced adolescents with more serious LTCs (i.e. cancer) as interviewers, because it could compromise their well-being to discuss issues with participants which they had also experienced (509). It was concluded that co-production with adolescents with LTCs requires a great deal of support, and should ideally be instigated by the adolescents to ensure their interest and commitment, as co-production is expensive in terms of both time and resources, so can be challenging to achieve (509). However, despite the challenges, efforts should be made to involve adolescents as much as possible in service and intervention development to achieve optimum user-friendliness and acceptability.

8.4.3 Implications for future research

Chapter 7 describes future plans for implementing and testing, including pilot, feasibility and process evaluations, of the *It's my body, I can have a say"* booklet. Further research would include a full scale RCT of the implemented booklet based on the results of the testing. To my knowledge, there have been no RCTs of interventions aimed at supporting SDM amongst adolescents with LTCs. A systematic review of interventions to support young people's engagement in healthcare decisions included five studies, two of which included RCTs in chronic care (152). However, these interventions addressed decision-making around risk behaviours and end of life decision-making, and aimed to improve effective decision-making, as opposed SDM (70, 152, 543). Two other systematic reviews which sought to locate RCTs of interventions to promote SDM in young people with cancer and cystic fibrosis retrieved no studies (115, 153). Upon completion of the pilot, feasibility, and process evaluation, a full-scale RCT of the booklet would be a novel

and important study to evaluate the impact of an intervention aimed to prepare and support SDM with an adolescent population.

Participants included in this thesis were recruited from paediatric and young adult (transitional clinics), therefore none of the responders had already transitioned to adult clinics. This was because many young people with LTCs do not transition to adult care until 19 years of age and older, and most patients attending the adult clinics would not have been eligible to meet the inclusion criteria. Transition is often met with reports of negative emotions due to dissolution of relationships and service gaps (537). This is therefore likely to have an impact on SDM attitudes and behaviours. It would be useful to repeat the qualitative studies described in this thesis with adolescents' post-transition in order to draw comparisons, and account for this population. This could also allow for the inclusion of elements related to transition preparation within the intervention.

The systematic review (Chapter 2) found that adolescents with LTCs wanted parents to have less involvement in the decision-making process. This was re-iterated in the reports from qualitative interviews (Chapter 4) where it was generally preferred that parents play a supporting role. Parents were therefore purposefully omitted from the intervention development process, which ensured that the intervention development was guided by the adolescent voice. However, with the inclusion of a 'parents' page', it would be useful to conduct focus groups with parents regarding this section of the booklet in order to evaluate its acceptability, and generate feedback around areas for improvement. Furthermore, as outlined above, parents are an important element of the SDM process, and it is apparent that they also need support in order to effectively support their child's involvement. The processes outlined in this thesis could be repeated to develop a separate intervention aimed at parents of adolescents with LTCs to prepare and support them to foster their child's involvement.

8.4.4. Impact of coronavirus (COVID-19)

Since conducting the research outlined in this thesis, drastic changes have been experienced by people worldwide due to the impact of coronavirus (COVID-19). The impact of COVID-19 may be particularly felt by young people, who have been found to be one of the groups worst-affected by the pandemic in terms of mental health

outcomes, where following the first UK lockdown in March 2020, the proportion of young people not able to concentrate doubled and of those not able to enjoy day-to-day activities tripled (544). Childline has reported a steady increase in counselling sessions, with an increase in young people discussing issues around mental health, struggling with feelings of depression and anxiety, and feeling lonely or isolated; family relationships, including stressful home environments; and school, including worries about future prospects (545). In addition, it was found that 40% adolescents in the UK reported feeling more anxious than before the impact of the COVID-19 pandemic (546).

Adolescents with LTCs, who are already at higher risk of low well-being than the general adolescent population, may be disproportionately affected by the pandemic (6, 547, 548). For example, 83% adolescents with mental health needs felt that the pandemic had made their mental health worse, with 31% stating "much worse" and 26% saying they longer had access to any support (549). Many adolescents with LTCs, such as diabetes, cancer, those taking immunosuppressant medications, and those with kidney, heart, and respiratory conditions have been classed as clinically vulnerable to COVID-19. They may have increased anxieties around contracting the virus and have had to take additional care such as shielding, possibly leading to increased isolation and loneliness. As discussed throughout the thesis, adolescents with LTCs do not want to feel or be seen different from their peers, and further differentiation due to clinical vulnerability could be adversely impacting health and well-being, which needs to be taken into consideration in healthcare delivery. Further research may be necessary to assess any changes in the needs and priorities of adolescents with LTCs following the impacts of COVID-19.

Health services in Wales have had to change significantly in the way they are used and delivered to reduce risk of infection, having a profound impact on both staff and patients (550). Many patient services have transitioned from face-to-face to digital models, and all paper based materials have been removed from waiting rooms to prevent multiple handling (550). If current operational frameworks are to remain the same, a paper-based intervention would no longer be fit for purpose.

However, the link to the booklet in its electronic format and accompanying video could be sent to patients electronically, and QR codes could be available for access

on posters in the waiting rooms. This would need to be taken into consideration when designing the implementation plan for evaluation of the "*It's my body, I can have a say*" booklet, with patients being provided digital versions of the intervention instead of hard copies described in Chapter 7. In addition, the impact of COVID-19 may affect all aspects of the research design, with research funding potentially decreasing and social distancing meaning changes in data collection process, including moving to online interviews, focus groups, and steering group meetings (551).

Shifting online for research operations and service delivery may provide increased flexibility for some. For example, those who have decreased mobility or who live rurally may find it easier to participate in research or access services. However, there issues which need to be considered differently when conducting research online, including privacy and access. It is important to consider those at risk of digital exclusion, which may exacerbate existing inequalities. Some families may not have access to online materials or support, often requiring costly data plans or a home broadband connection, which 7% of British households do not have (552). Adolescents without internet access may already be excluded from online meetups with friends or schoolwork, as many schools continue to close due to infection rates, including secondary schools in Wales closing early for the Christmas school holidays. In addition, the Institute for Fiscal Studies reported that UK young people from better-off families spent 30% more time learning at home during school closures than those from families in the lower income brackets, and that lower incomed households were around 15% less likely to have access to active resources from schools, such as online classes, or video or text chatting (553). Adolescents from lower income households may therefore experience exclusion in many areas of life, which can affect their healthcare and representation in research as well as their well-being and future prospects. This needs to be considered by researchers and healthcare services, with efforts made to reduce risk of exclusion and to ensure that those with health needs are not missing out on the necessary support.

8.5 Strengths and limitations of the research presented in this thesis

8.5.1 Sampling

Although purposive sampling was attempted to recruit participants with a roughly equal distribution of age, sex and LTC, this was not achieved. Recruitment at the various stages of the PhD proved to be more difficult than I had anticipated. Adolescents are a hard-to-reach population, and recruitment has been previously described as challenging (554-556). In my current role as a Social Researcher at the Office for National Statistics interviewing adolescents about wellbeing, I have discovered similar issues with recruiting young participants.

Above, I discussed the implications of deviations around sense of normality on SDM involvement. Adolescents with LTCs may prefer not to participate in discussions around their LTC to preserve their sense of self, disassociated from the "*patienthood*" identity. This might have further affected willingness to participate in a research project which involves discussing their LTC. This could also have implications when undertaking the proposed protocol for pilot and feasibility testing, for which the recommended sample size for randomisation is 80. A full-scale RCT may be challenging due to recruitment issues.

Males were underrepresented in the sample, as they were less likely to respond (Chapter 4). Furthermore, due to loss of contact with a paediatric rheumatology HCP, only two participants were recruited from this clinic. I continued to interview female respondents and those from the other clinics as I did not want to deprive those who volunteered of the opportunity to be involved. As Miriam (aged 15) described, just being involved in the research made her feel as though she had a voice, and expressed intention to be more involved in future decision-making as a result of the process. Young people most often chose to be involved in research because they want to "*inform change and improve children and young people's lives*" (557). As a strong advocate for inclusion and empowerment of young people, it would seem unethical to disallow participation of those eligible who responded based on their sex or type of LTC.

Reasons for non-response were unavailable as all but one of the participants approached agreed to participate, but most did not respond. It would be useful to have been able to gain insight into why certain adolescents with LTCs decided not to

follow-up. It is likely that those who decided not to engage as participants are less likely to choose to engage in the decision-making process with HCPs. Therefore, the findings of the PhD may be skewed towards those who are already actively vocal. However, although the token of appreciation in the form vouchers was not intended to incentivise participants, this may have been the case, which could have resulted in a response from those who may not have otherwise been involved. As noted in Chapter 4, recruitment improved considerably after changing the voucher supplier and increasing its value.

Participants in the focus groups were recruited through youth workers from paediatric endocrinology and nephrology clinics who arranged meet-up groups with attending adolescents. This was considered to be a good recruitment strategy, as the youth workers are trusted source, and likely to provide access those might not otherwise volunteer engage in research. Furthermore, the focus groups took place after the prearranged meet-up event to provide minimal disruption to participants, and ease organisation.

However, there is the potential for issues regarding selection bias. The youth workers may have selected participants based on who they felt were the most outgoing and talkative. Furthermore, those who already engage in social groups and meet-up events may be more likely to engage in other aspects of life (e.g., SDM). This has implications for representativeness; although piggybacking on existing groups was a useful and effective method for recruiting individuals to a focus group session, such groups may also not be truly representative of the target population. The inductive qualitative approach enabled the discovery of issues which had not been previously anticipated. However, qualitative research by nature cannot be generalised, and should be complemented with studies containing much larger samples. Also, data on the numbers of individuals invited to take part, or their reasons for refusal, were unavailable. Therefore, the response rate and reasons for non-participation in the focus group study were unknown.

The intervention outlined in this thesis was developed for adolescents with a wide range of LTCs to prepare and support their participation in SDM. However, although some of the previous research and literature outlined and referenced in this thesis explores experiences of adolescents with long-term mental health conditions and

their involvement in SDM (136, 139, 140, 144, 146, 212, 254, 271, 415, 418), I did not recruit adolescents from mental health services. Some participants in the qualitative interviews discussed their experiences with mental health, such as mental health issues as a result of dealing with their LTC and medication side-effects, and decision-making experiences with psychologists were included in pie charts. However, it would be useful to also assess the usefulness and acceptability of the *"It's my body, I can have a say"* intervention for its use with adolescents with long-term mental health conditions using mental health services, and explore any potential differences in SDM barriers and facilitators between mental and physical LTC healthcare in order to determine whether adjustments need to be made to the intervention and its implementation.

8.5.2 Intervention development

The IMA was used alongside the Person-Based Approach in accordance with the MRC framework to guide intervention development for this PhD, and was useful in this context. This approach was selected due to its systematic and user-centred properties. However, there are assumptions which need to be acknowledged. The IMA assumes that all behaviours and environmental conditions that cause the health problem are identified in stage 1 (needs assessment). With minimal pre-existing literature and a small sample size for qualitative exploration, there is the potential that key determinants were omitted from the assessment.

The IMA also assumes that achieving more favourable behavioural/environmental outcomes leads to improving the health problem (a lack of SDM) and therefore quality of life. As discussed in Chapter 1, if adolescents are pushed to be involved in the decision-making process beyond their comfort levels, this may have a negative emotional effect, which could negatively impact quality of life. For this reason, quality of life was proposed as a key outcome measure for the proposed feasibility and pilot RCT protocol (Chapter 7).

In line with the Person Centred Approach (200), intervention development was intended to be guided by the users' (adolescents with LTCs) voice. HCPs were included in the pre-testing (Chapter 6) to ensure acceptability of the intervention, gain insight into implementation within the clinical pathways, and improve HCP buy-in. However, the interview schedule could have included more focus on

implementation, eliciting ideas for specific steps, and potential barriers. Therefore, Chapter 7 emphasises the importance of an established stakeholder group, including adolescents with LTCs, parents, and clinical team members, in order for effective implementation and testing to be undertaken.

As discussed in Chapter 4, booklet or leaflet was the most common suggestion for an intervention (described as health materials) by adolescents with LTCs, which may have been due to availability or familiarity heuristic. This refers to the phenomenon where people opt for the more familiar options, even if the result is less favourable than available alternatives, as participants said they had received paper-based health materials in the past. Limitations of patient information leaflets include being inaccessible to patients with lower health literacy, which may increase health inequalities (558). The short video accompanying the booklet aims to provide the key points in a more accessible format, which is a strength of the intervention, but has yet to be tested with adolescents with LTCs or HCPs.

Children's Health Information Matters Project (IMP), published in conjunction with the NIHR, included an in-depth review of interventions used in the NHS to support and empower young people and their families' decision-making and health choices through information provision. The project also included patient observations, focus groups and interviews with over 150 participants including young people aged six to eighteen, their families and HCPs. IMP found that young people placed greater importance on the information presentation and relevance as opposed to type (e.g. app, book website) but generally disliked detailed text (559). Avoiding lengthy texted had also been recommended by adolescents with LTCs in the interviews outlined in Chapter 4, and therefore the "*It's my body, I can have a say*" booklet presents information using bullet points and short paragraphs. IMP also concluded that young people require individually-targeted interventions and support to enable them to participate fully in consultations and decision-making, as the appropriateness of different information types largely depends on context, the individual, the specific decision to be made and related options (559). The paper booklet with accompanying online version and video were designed to be tailored to individual contexts and provide a selection of mediums. However, as one of the participants stated in the booklet pre-testing (Chapter 6), the cartoon images may be viewed as overly childish therefore not age appropriate, and adolescents may prefer images of

"real" patients (559). IMP recommends that intervention developers need to ensure the interventions are produced with young people to ensure they are young people friendly (559). Adolescents were involved in providing feedback on, and selecting images from options provided by the designer, as well as in the booklet pre-testing including suggestions for improvements (Chapter 6). However, this process could have been more collaborative, with adolescents involved in the intervention creation and drafting as opposed to merely selecting and commenting on pre-designed images, for example developing collective storyboards outlining what the intervention should look like to provide the designer as guidance (560). This is one of many examples where this PhD project could have benefited from greater co-production.

8.5.2.1 Co-production

Bartholomew and colleagues (201) do not provide specific guidance on how to involve stakeholders in intervention development, although some examples of IMA report established stakeholder steering groups to guide the entire process (561-563). At the beginning of the PhD, the approach to intervention development had not yet been decided, so no working stakeholder group was established. I tried to overcome this shortcoming by consulting a group of adolescents who were known to me at various stages of data collection and intervention development, to ensure age-appropriateness and acceptability. I regularly consulted with supervisors who are a group of SDM experts including one general practitioner, as well as a paediatric endocrinologist who sat on my advisory panel (JG). However, more efforts could have been made to involve stakeholders at all the research stages, including the research design. Regular meetings with a stakeholder group would have enabled greater collaboration and more input to be contributed by those for whom the intervention is intended to be used throughout the development process. This group could consist of HCPs, parents, adolescents with LTCs, and SDM experts to provide viewpoints from all relevant angles.

Patients are increasingly involved as equal partners in research, which should include involvement in all research activities from start to finish, focusing on experiential knowledge and expertise, and mutual learning (564). Realistically, participation costs can include heavy demand on time and additional burden of work (540, 565). With an already hard to reach population, the process of involving

adolescents with LTCs in the data collection and analysis could have been beyond the capacity of this PhD.

However, in retrospect this research project could have benefited from a stronger element of co-production from the beginning without being overly burdensome. Firstly, although the participatory methods (Chapter 4) were piloted with two adolescent males, it would have been useful to obtain further feedback from the participants on the data collection methods. I could have done this by including questions within the interview schedule to elicit perspectives around being involved in the research process, including suggestions for improvements. Secondly, the think-aloud technique and interview schedule used in the focus groups were not piloted with a group of adolescents, which resulted in complications with the first group (described in Chapter 6). Although this approach was revisited and rectified for the second group with success, this could have been avoided and perhaps richer data could have been collected in the first session had adolescents been effectively involved in piloting beforehand as well as the decision-making around data collection. Had adolescents with LTCs been more involved as co-researchers of this project from the beginning, including involvement in decision-making around research aims and design, such as recruitment, data collection, analysis, and dissemination, it would have provided more opportunity for their voices to be more deeply embedded in the research and intervention development, resulting in an intervention fully, as opposed to party, developed by the users thus improving intervention acceptability and potential for effectiveness (200).

8.6 Reflexivity and reflection

Reflexivity refers to a researcher's awareness of how their previous experiences, personal values and assumptions as well as other influences, including research colleagues or supervisory team, may have contributed to the research process (566). The reflexive process involves communicating these potential influences in relation to the research and outlining how these may have shaped the researchers' understanding and interpretation, and in turn data collection and analysis, of the research topic.

As discussed in the positionality section in Chapter 4, I have experienced living with LTCs from childhood. Although my conditions were likely milder and less intrusive

than the LTCs discussed in this thesis, I have experienced LTC services including healthcare decision-making and condition management, particularly in childhood and adolescence when my conditions were most severe. Having shared experiences with the research participants involved in this PhD project has had potential advantages and disadvantage as well as challenges throughout the course of the PhD.

My shared experiences may have helped me to more easily grasp and understand the topic area as well as the nuanced reactions of the participants, which in turn could have enabled me to probe more effectively and recognize clues that others might miss (567). When listening to and analysing participants' narratives of various challenges with their LTC and decision-making involvement, I recalled my struggles with similar issues. For example, I knew well about the feelings of wanting to live a normal life and not wanting to be differentiated from peers expressed by the adolescents participants. During the interviews I recalled wearing long trousers and sleeves on hot summer days as not to expose my eczema, and suffering through heart palpitations during activities in physical education classes at school as I did not want to be excluded.

However, familiarity with participants' experiences can be accompanied by the risk of blurring boundaries, imposing your own beliefs and assumptions on the data (567). A constant deliberate effort was required to maintain the participants' experiences separate from my own (567). Although my reflective attentiveness has developed since I first began conducting the qualitative interviews, I believe I took sufficient care to enable participants to tell their stories, providing their narratives of their own experiences without my leading in any specific direction on the basis of my own biases and experiences. I did this by taking field notes during and after each interview or focus groups to capture my own emotional responses, reactions, and impressions (see Chapter 4). I found this process helpful in helping to separate my experiences from those of the participants, and it is a process I shall continue throughout my qualitative research career.

However, despite these efforts, I may have failed to manage my biases effectively at all times. For example, upon reflection, my decision not to include parents in the intervention development may have been somewhat guided by my own experiences and feelings of my views being overruled by those of my parents at the time.

However, my justification for the research design derived from the initial systematic review, from which findings included the underrepresentation of the voices of adolescents with LTCs both in research and in clinical encounters, including reports of parents blocking adolescents' attempts at involvement. Therefore, I thought it was most appropriate for the intervention to be guided entirely by the adolescent voice. Although I attempted to provide a balanced account of parents' roles as both supporting and hindering their child's participation throughout the thesis, I may have unintentionally overemphasised the blocking role. Had the research process followed a more co-productive model, including involving adolescents with LTCs in the generation the project aims and objectives as well as the research design and stages for intervention development, I may have been able to better manage these assumptions and have had better insight into how best to represent the views and values of adolescents with LTCs.

I hold strong beliefs that children and adolescents should be more actively involved in many areas of their lives, including their healthcare and research. However, reflecting on the key principles of SDM (i.e., a collaborative approach putting the patient at the centre of decisions), I may have neglected to follow these principles in my own research, thus following a more paternalistic approach. Although I attempted to involve adolescents with LTCs in the intervention development, many of the project decisions (e.g., aims and methodology) were not shared there were several missed opportunities for co-production, particularly in the early stages of the research. This mirrors HCPs beliefs that SDM is the right thing to do, which is often not reflected in practice (92). Early planning for co-production at the initial stages of the PhD would have been necessary to ensure the support and resources were available to fully co-produce the research and intervention with adolescents throughout the project timeline.

As an example, one stage I found particularly challenging was recruitment. I spent many hours in secondary care clinics speaking to adolescents and parents who stated an interest in the project and in being involved, but then did not respond. At the time, I had not considered speaking to adolescents about this process, involving them in decisions about recruitment strategies, which would have likely improved the recruitment outcomes. The challenges I experienced at initial recruitment stages likely influenced later decisions for the intervention pre-testing, which involved

piggybacking on pre-existing meetup groups. This had limitations, as discussed previously, which may have been avoided had a different strategy been chosen in collaboration with adolescents with LTCs.

My professional background is health psychology, a field which looks at how to understand and promote general well-being and physical wellness, including the study of behavioural process relating to health, illness, and healthcare. To do this, health psychology relies on a plethora of behavioural theories and models, with which accompany assumptions that individuals are generally aware of their own behaviours and that wellness is something people strive for. My educational background is likely to have influenced my understanding and interpretation of data by way of the selection of theory underpinning the intervention and intervention development. However, all attempts were made to guide theory selection by the adolescents' narratives. Efforts were also made to minimise these biases through discussions with the supervisory team with backgrounds in different fields, including sociology and medicine. My assumptions were continuously challenged by my supervisory team, as well as through the double coding of data and discussions with research colleagues.

My supervisors acted as a sounding board for decision-making throughout the research processes, constantly questioning my ideas and decision processes in order to ensure my reasonings were well justified. However, as I looked up to my supervisors and sought their approval, my decisions may have been inadvertently influenced by their previous work, which is widely referenced throughout this thesis. For example, this may have resulted in selecting the three talk model (100) for SDM, of which two of my supervisors co-authored the earlier paper (98), as the basis for the intervention development, with perhaps insufficient consideration of alternatives. This model has been criticised for its use in paediatrics, as it was developed for adult patients with a dyadic relationship in mind (399). However, this is a widely utilised and referenced model, which has, since the "*It's my body, I can have a say*" booklet was developed, been adapted for use with adolescents with LTCs, maintaining the three step approach to SDM (399). In addition, the three talk model was used in this thesis alongside the Makoul Clayman's integrative SDM model, derived from a systematic review including 31 separate concepts (99).

8.7 Conclusion

Adolescents with LTCs desire to be involved in SDM, but their actual level of involvement during consultations is low. Preferences for involvement often differ, and can fluctuate, depending on individual or decisional circumstances. Most explain their marginalised position as a result of individual (capability and motivation) and social (opportunity) factors. Parents, adolescents, and HCPs all need support to foster adolescents' involvement in SDM. The complex dynamics of the triadic encounter can lead adolescents to feel they have no real control. Adolescents with LTCs are ambivalent about their parents' role: while they need their parents and often appreciate their support, they also feel not at ease when parents 'interfere'. Adolescents with LTCs do not want to be treated differently from their peers, and need to feel that SDM involvement aligns with their sense of what is normal in order to participate. The intervention developed as a result of the exploration of adolescents' narratives has the potential to encourage and support adolescent involvement in SDM through normalisation, simplifying the process, raising awareness of the possible benefits, and clarifying that adolescents' involvement and input is valued by their clinical team members. HCPs' communication with adolescents with LTCs should aim to create a trusting space, where adolescents feel they can communicate openly about preferences and concerns. The onus of responsibility should not be on the adolescents to 'speak out', but on adults to ensure views are sought. This will help adolescents with LTCs to feel they really can have a say.

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Appendices

Appendix 1. Chapter 2 – Patient Education and Counselling publication
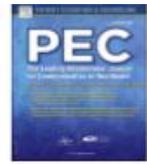
Review article

What adolescents living with long-term conditions say about being involved in decision-making about their healthcare: A systematic review and narrative synthesis of preferences and experiences

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ABSTRACT

Objective: To understand the preferences and experiences of adolescents (age 10–19) with long-term conditions (LTCs) towards involvement in discussions and decisions regarding management of their condition.
Methods: A systematic review and narrative synthesis of mixed-methods, quantitative and qualitative and research was performed. Six databases were searched from inception to March 2017. The quality of the articles was assessed, and relevant data were extracted and coded thematically.
Results: The search yielded 27 articles which met the inclusion criteria. Decision-making involvement preferences and experiences were reported from the adolescents' perspectives. Adolescents often report that they do not have any choice of treatment options. Variability in preferences and experiences were found within and between individuals. Mismatches between preferences and experiences are common, and often with negative emotional consequences.
Discussion: Adolescent preferences for involvement in the decision-making process are situational and individualistic. Healthcare professionals can encourage involvement by ensuring that adolescents are informed of treatment options, and aware of the value of their contribution. Future research should explore adolescent perceived barriers and facilitators to SDM.
Practical implications: Interventions are needed to effectively train HCPs in the delivery of shared decision-making, and to support the participation of adolescents with LTCs in shared decision-making.

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Contents

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1. Introduction

Adolescence is a critical period of psychosocial development in which people experience a change in interpersonal roles, responsibilities and identity [1,2]. Unsurprisingly, these years can be more complex for those living with a long-term health condition (LTC). Adolescents with LTCs increasingly take on self-management responsibility, sometimes doing the majority of self-care tasks by the age of 13 [3–7]. However, self-management and health outcomes of patients with LTCs often decline during adolescence, which can lead to increased likelihood health complications and hospital admissions [7–9].

Current recommendations state that adolescents should be encouraged and supported to participate in healthcare decisions [10,11], and the ability of adolescents with LTCs to make informed and thoughtful decisions about their healthcare has been documented [12,13]. Healthcare decision-making around LTCs has been described as a continual process, with no clear beginning or end; where numerous decisions are taken, evaluated and often reevaluated [14]. Montori et al. emphasise the need for patients to take a more active role in treatment decision-making in a long-term care setting, which offers a longer window of opportunity to make decisions, and to revisit and reverse them without important loss, compared to patients in acute care settings where decisions are often urgent and may be irreversible [15]. Shared decision-making (SDM) provides the opportunity for patients with LTCs to evaluate the risks, benefits and costs of various management options and procedures for their condition, while enabling a shared understanding of preferences and possible issues, such as difficulties with side-effects or in performing self-management tasks [16]. SDM interventions in paediatric medicine have been found to be associated with improved knowledge and reduced decisional conflict [17].

Previous research in decision-making in paediatrics has predominantly focused on interactions between the parent and healthcare professionals (HCPs) [17]. The presence of a triadic relationship is an important distinction between child and adult consultations, where parent involvement can prevent SDM from occurring between the young patient and HCP [18]. A review [19], which identified literature addressing adolescents', parents' and HCPs' experiences of decision-making in paediatrics, found that adolescents' views in health consultations were rarely sought or acknowledged. However, most of the studies in the review did not actually explore the patients' perspectives. This is reflective of the exchange during a paediatric consultation, where adolescents' voices are rarely heard, and they tend to act as bystanders [20,21]. It is important to understand how adolescents experience discussions and decision-making during consultations in a healthcare setting, as well as their preferences for involvement. Understanding the perspectives of adolescents with LTCs regarding their experienced and desired roles in the decision-making process can help us to further understand their support needs.

1.1. Aim & objectives

The aim of this review was to collect and synthesise published research data on adolescent perspectives towards involvement. The objectives were to: (a) understand the preferences of adolescents with LTCs towards being involved in the decision-making process about their condition management; (b) understand the experiences of adolescents with LTCs with involvement in the decision-making process and (c) make recommendations regarding how SDM with adolescents with LTCs can be implemented.

2. Methods

The review applied a systematic search methodology following the PRISMA statement [22] and in accordance with the guidance on the conduct of a narrative synthesis [23]. The protocol was prospectively registered on PROSPERO [24] (CRD42017055650).

2.1. Eligibility criteria

Included studies were English-language qualitative, quantitative and mixed-method papers which report empirical research about the preferences and/or experiences of adolescents living with one or more LTCs, from the patient perspective. No limitations were placed on the year of publication. An age range for adolescents of 10–19 years was stipulated in accordance with the WHO definition. Studies with participants of an age outside of the adolescent parameters were included if the measure of central tendency fell within the 10–19 year-old range. LTCs were defined as conditions requiring 'ongoing management over a period of years or decades' [25]; meaning conditions which require continuing clinical care and self-management. Examples include diabetes, asthma and cancer. Due to the small number of eligible papers, studies were not excluded if the sample also included acutely ill patients.

For inclusion, papers had to examine the decision-making process in a healthcare setting regarding decisions that are characteristic to LTC care. This means ongoing condition management discussions and decision-making, such as decisions about, diet, exercises, appointment scheduling, medication administration, or treatment plans. Papers which primarily examined other types of decisions such as research participation, fertility preservation, or end of life decisions, were excluded. Studies containing mixed samples (e.g. perspectives of adolescents, parents and HCPs) were included if the adolescents generated data were reported separately or could be separated by the reviewers. Data which made comparisons between adolescent and HCP/parent responses were retained. Papers which reported studies with wholly parent or HCP samples were excluded.

2.2. Systematic search

Six electronic bibliographic databases (Embase, Medline, Cochrane Library, CINAHL, PsycINFO and Scopus) were searched systematically from inception to March 2017 in order to identify

potentially eligible articles. Ethos, Open Grey, The New York Academy of Medicine Library and ADOLEC (Adolescent Health) were searched for grey literature, such as documents published by governments and non-governmental organisations. A comprehensive strategy was developed with key search terms across titles and abstracts, or as medical subject headings using the Boolean operators 'AND' to combine key concepts, and 'OR' for synonymous keywords (Fig. 1). Key search terms included a string for 'adolescents', and combinations of strings for decision-making and HCPs, which was adapted from the Legaré et al. systematic review [26]. Relevant papers were also sought using the 'pearl-growing' technique, in which further studies are identified by examining the reference pages of relevant papers [27]. Papers identified from the initial database searches were imported to EndNote X8 [28] and duplicates removed. Remaining titles and abstracts were then screened for relevance by one author (AJ); those that did not meet the inclusion criteria were removed. The full texts of all the remaining records were assessed for eligibility by two authors (AJ, VS) independently, and the reasons for exclusions stated (Fig. 2). Resolution of discrepancies was sought through discussion involving a third researcher (FW).

2.3. Critical appraisal of included studies

The quality of included studies was assessed using existing criteria designed for appraising the appropriate type of study (CASP|AXIS) [29,30] (AJ). Ten per cent of the studies was quality assessed by a second author independently (VS). Both authors were in agreement, therefore it was decided no further duplication of effort was required. Due to the small number of eligible studies,

none were excluded on the basis of overall quality, but important methodological issues were noted and taken into consideration during the data synthesis.

2.4. Data extraction

The data from the studies were extracted according to basic study characteristics, including study aims, design, sample demographics, and care setting; definition of decision-making involvement and adolescent reported preferences and experiences (Table 1). Where necessary, corresponding authors of included studies were contacted to obtain specific information. Two authors extracted the data for all included studies independently (AJ, VS). The relevant data were entered into NVivo11 for coding support and quotation retrieval [31].

2.5. Data synthesis

Due to the lack of homogeneity in the eligible studies, a meta-analysis of the results was impossible. The analysis was conducted following Popay et al's. [23] guidance. This involves using words and text to summarise and explore data from differing methodologies, and organises the output as a synthesis to 'tell a story'. A preliminary synthesis was developed, involving the coding and organising the extracted data which were relevant to the research question. Braun and Clarke's [32] thematic analysis was used to extract, code, organise and report patterns or themes of the relevant data. The data set was coded inductively, and the codes were grouped into overarching themes. The themes were discussed and refined until a coherent pattern had been formed,

#1
shared decision*.ti,ab. or sharing decision*.ti,ab. or informed decision*.ti,ab. or informed choice*.ti,ab. or decision aid*.ti,ab. or ((share*.ti. or sharing.ti. or informed*.ti.) and (decision*.ti. or deciding.ti. or choice*.ti.))

#2
*clinical decision making/ or *decision making/or *decision support system/ or *ethical decision making/ or *family decision making/ or *medical decision making/ or *patient decision making/or decision making*.ti,ab. or decision support*.ti,ab. or choice behaviour*.ti,ab. or ((decision*.ti. or choice*.ti.) and (making*.ti. or support*.ti. or behaviour*.ti.))

#3
patient participation/ or patient participation.ti,ab. or consumer participation*.ti,ab. or patient involvement*.ti,ab. or consumer involvement*.ti,ab. or ((patient*.ti. or consumer*.ti.) and (involvement*.ti. or involving*.ti. or participation*.ti. or participating*.ti.))

#4
*doctor patient relation/ or *nurse patient relationship/or ((*nurse/ or *physician/ or nurse*.ti or physician*.ti or clinician*.ti. or doctor*.ti. or general practitioners*.ti. or gps*.ti. or health care professionals*.ti. or healthcare professionals*.ti. or health care providers*.ti. or healthcare providers*.ti. or resident*.ti.) and (*patient/ or patient*.ti. or consumer*.ti. or people*.ti.))

#5
*child/ or *adolescent/ or kid*.ti,ab or *minors/ or minor*.ti, ab or child*.ti,ab. or pediatric*. ti,ab. or paediatric*.ti,ab. or adolescen*.ti,ab. or youth*.ti,ab. or teen*.ti,ab. or (young adj3 people).ti,ab. or (young adj3 person).ti,ab.

#6
(1 or (2 and 3) or (2 and 4) or (3 and 4)) and 5

**Fig. 1.** Example Search Strategy: OVID- Medline.
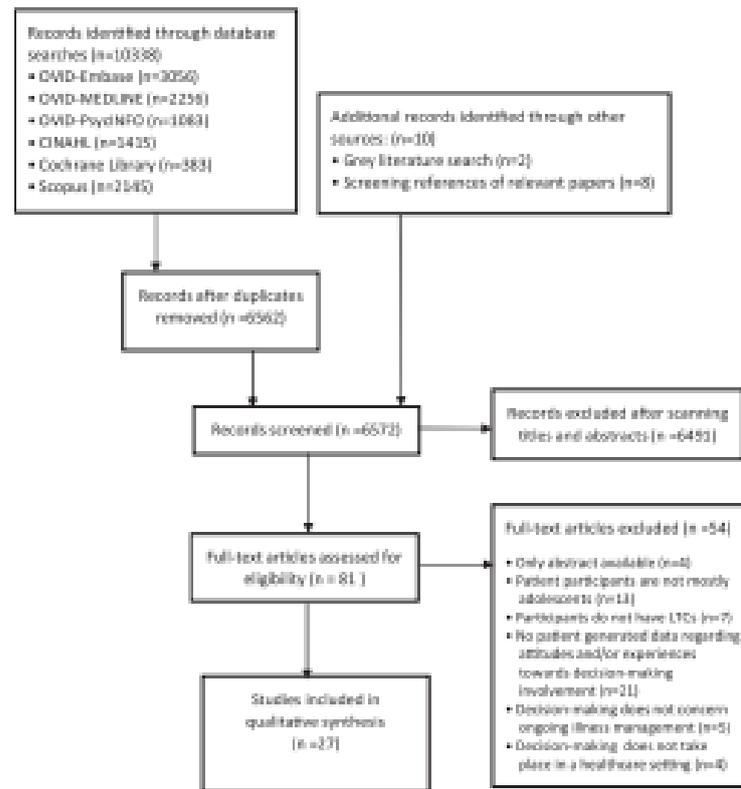
Fig. 2. PRISMA [21] flow diagram with reasons for exclusion.

and a summary of each theme was written out. The studies were then revisited to ensure the themes provided a sound representation of the relevant data.

3. Results

3.1. Systematic search

We retrieved 10,388 studies; 6572 were assessed against the inclusion criteria after duplicates were removed, and 27 papers [33–59] were included in the review (Fig. 2). Studies originated from seven countries: nearly half (n = 11) from the United States, other countries of origin include Canada (n = 2), Australia (n = 2) and European countries (n = 12). All except three were published between 2006 and 2016. Included studies employed qualitative (n = 17), quantitative (n = 6), and mixed methods (n = 4). Study samples included adolescents with cancer [37,40,41,45,51–53,56,58,59], diabetes [39], cerebral palsy [43,57], immune thrombocytopenia [34], a mix of LTCs [33,35,44,47,49,50,55] or combined LTCs and acute illnesses [37,46,54]. No studies focussing on mental health conditions met the inclusion criteria. Study characteristics are reported in Table 1.

3.2. Quality appraisal

All studies were appraised as including a clear statement of aims with an appropriate research methodology, design and recruitment strategy to address the aims. However, issues of reflexivity were only considered in one paper [56]. This is especially important due to the potential for perceived power

imbalance between the researcher(s) and young participants, and it is important to consider the researcher(s) own role, potential bias and influence on the research outcomes. Furthermore, non-respondent characteristics were not reported in most studies. These data could be meaningful due to a potential association between those who participate in research and those who are involved during health consultations. Most papers provided clear and explicit findings, which add a valuable contribution to the area of literature [33–46,48–52,54–58].

3.3. Synthesis of findings

The data reflected involvement in the decision-making process from the adolescent perspective, where parents, adolescents and HCPs were involved at varying levels. This includes involvement in the exchange of information, as well as discussions and decisions. In response to the first two review objectives the data were grouped as either preferences or experiences. Preferences refers to the expressed wishes, views and opinions of the young patients towards the different decision-making stages. Experiences represents the young person's reality, what they have experienced and how it affects them. The grouping of data into preferences and experiences allowed for comparisons to be made between what adolescents want, and what their reality is. Codes were created and grouped into three overarching themes, and are summarised below: variability in involvement preferences and experiences, power dynamics and involvement in the decision-making process, and mismatch between involvement preferences and experiences (number of studies coded at each theme). Table 2 provides examples of quotations coded at each of the themes.

Table 1
Table of included studies.

Study: Author, Ref., Country	Study aims	Design	Patient population characteristics	Health Condition (s) and setting	Patient Age range	Definition of involvement
Angst and Deatrick [33], United States	To describe how children with LTCs and their parents are involved in healthcare decisions through a secondary analysis of two data sets	Qualitative: interviews	N = 28 46% female	Cystic fibrosis (71%) and scoliosis (29%)/Secondary care	7–19	Contribution towards decisions related to their health or illness
Beck et al. [34], Canada	To examine the treatment decision-making process for hospitalised children	Qualitative: focus groups	N = 7 14% female	Immune thrombocytopenia/ Secondary care	10–18	SDM: exchanging information about medical evidence and patient preferences, and identifying which course of action is most consistent with those preferences
Bejarano et al. [35], United States	To evaluate the feasibility and acceptability of SDM interventions	Quantitative: Pre-post experimental design	N = 26 50% female	Environmental allergies (58%) and scoliosis (42%)/ Secondary care: specialist clinic	5–17	SDM: accommodating patient preferences and values in making decisions about their care
Coyne [36], United Kingdom	To explore children's, parents' and nurses' views on participation in care in the healthcare setting	Qualitative: in-depth interviews and participant observation	N = 11 64% female*	Various long-term and acute/ Secondary care: inpatient	*7–14	Being consulted and involved in decisions about their care
Coyne and Gallagher [37], Ireland	To explore hospitalised young people's experiences of participation in communication and decision-making	Qualitative: interviews and focus groups	N = 55 44% female	Various long-term and acute/ Secondary care: Inpatient	7–18	Being active partners in decisions about their health and care and, where possible, being able to exercise choice
Coyne et al. [38], Ireland	To explore children's participation in shared decision-making.	Qualitative: interviews	N = 20 45% female	Cancer/Secondary care: Inpatient and day care units	7–16	SDM: contribution to the decision-making process, independent of who makes the final decision.
Croom [39], United States	To examine the relationship between perceived patient-centred communication and patient empowerment and diabetes management.	Quantitative: Cross-sectional surveys and medical records	N = 190 52% female	Type 1 diabetes/ Secondary care: specialist clinic	10–15	Mutual exchange of information and reaching a shared understanding of patient problems and the treatments that are concordant with patient values.
Dunsmore and Quine [40], Australia	To identify patients' information, support and decision-making needs and preferences, and the extent to which those needs were being met.	Mixed Methods: Questionnaire including open and closed-ended questions	N = 51 47% female	Cancer/Secondary care	12–24	Information provision, and decision-making involvement.
Ellis and Leventhal [41], United States	To evaluate the information needs and decision-making preferences of children with cancer.	Quantitative: surveys	N = 50 40% female	Cancer/Secondary care	9–17	Information needs and decision-making preferences
Feenstra et al. [42], Canada	to evaluate the feasibility and acceptability of decision coaching	Quantitative: Pre-test/post-test	N = 7 43% female	Type 1 diabetes/ Secondary care: specialist clinic	9–17	SDM: exchange of information on options and treatment preferences to reach an agreement on treatment plan.
Garth et al. [43], Australia	To explore how the doctor–parent–child partnership is experienced and if the child patient is considered a contributor	Qualitative: Interviews	N = 10 70% female	Cerebral palsy/ Secondary care	8–12	Factors contributing to an effective partnership which include joint decision-making and open communication
Jedeloo et al. [44], The Netherlands	To uncover preferences for self-management and hospital care of adolescents with various long-term conditions.	Mixed methods: Interviews Q-methodology	N = 31 48% female	Various long-term/ Secondary care	12–19	Involvement in consultations, including decision-making styles.
Kelly et al. [45], United States	To better understand how children and adolescents viewed their treatment decision-making involvement	Qualitative: interactive interviews	N = 29 48% female	Cancer/Secondary care	9–17	Information provision and involvement in treatment decision-making
Kelsey et al. [46], United Kingdom	To explore young people's perceptions of their involvement in healthcare decisions affecting their management of care.	Qualitative: Interviews and recorded audio diaries	N = 10 40% female	Various long-term and acute/ Secondary care: Inpatient	13–16	Involvement in healthcare decisions
Knapp et al. [47], United States	To explore adolescents' involvement in, and preferences about SDM	Mixed methods: Surveys and interviews	N = 35 55% female	Various long-term/ Various care settings	14–21	SDM: participation in the decision-making by expressing preferences and coming to a mutual decision.
Knopf et al. [48], United States	To describe the decision-making preferences of adolescents with long-term conditions and their parents	Quantitative: surveys	N = 82 55% female	Various long-term conditions/ Secondary care	*11–19	SDM: shared information and collaboration to reach a decision
Lipstein et al. [49], United States	To understand adolescents' roles and preferences in long-term condition treatment decisions, using a biologic therapy decision as an example.	Qualitative interviews	N = 15 60% female	Crohn's disease (47%) and Juvenile idiopathic arthritis (53%)/Secondary care	12–17	Participation in medical decision-making
Lipstein et al. [50], United States	To compare factors considered by parents to those considered by adolescents when making	Qualitative interviews	N = 13 62% female	Crohn's disease (54%) and Juvenile idiopathic arthritis	13–18	Participation in LTC treatment decisions

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Table 1 (Continued)

Study: Author, Ref, Country	Study aims	Design	Patient population characteristics	Health Condition (s) and setting	Patient Age range	Definition of involvement
	decisions about long-term condition treatments.			(48%)/ Secondary care		
Ruhe et al. [51] Switzerland	To explore patients' perspectives on participation in discussions and decision-making surrounding their diagnosis.	Qualitative interview	N = 17 35% female	Cancer/ Secondary care	9–17	Participation in the form of receiving or providing information, contributing an opinion, or making healthcare choices
Ruhe et al. [52], Switzerland	To explore how patient participation was put into practice in a paediatric oncology setting	Qualitative interview	N = 17 35% female	Cancer/Secondary care	9–17	Participation in discussions and decision-making
Stegenga and Ward-Smith [53], United States	To explore treatment decision-making from the perspective of the adolescent	Qualitative interview	N = 3 67% female	Cancer/Secondary care	13–15	Participation in treatment decision-making
Taylor et al. [54], United Kingdom	To investigate child and carers' attitudes towards child involvement in paediatric consultations.	Qualitative interviews	N = 20 75% female	Various acute and long-term/ Secondary care: inpatient and outpatient	7–16	Involvement during consultations, including information sharing and ultimate decisions about treatment
Van Staa [55], The Netherlands	To evaluate adolescents' preferences and competencies for communication during consultations.	Mixed methods: Interviews, Q-methodology, Observations, Focus groups, Web questionnaire	N = 1021 55% female	Various long-term/ Secondary care	12–19	Healthcare communication, including making decisions
Weaver et al. [56], United States	To investigate adolescent medical decision-making preferences and the behaviours reported to be supportive of their preferred level of decision-making involvement.	Qualitative Interviews	N = 40 40% female	Cancer/Secondary care	12–18	Treatment decision involvement and information access.
Young et al. [57], United Kingdom	To examine and compare children's, parents' and practitioners' perspectives and experiences of decision-making in community paediatric physiotherapy services	Qualitative Interviews and focus groups	N = 11 45% female	Cerebral palsy/ Community care	8–18	SDM: involvement in the decision-making process by sharing information and expressing treatment preferences so that a decision is made and agreed by all parties
Zwaanswijk et al. [58], The Netherlands	To investigate communication preferences of young cancer patients, parents, and survivors of childhood cancer	Qualitative Online focus groups	N = 7 57% female	Cancer/Secondary care	8–16	Communication, including information exchange, decision-making and interacting.
Zwaanswijk et al. [59], The Netherlands	To investigate communication preferences and variables associated with these preferences.	Quantitative hypothetical: Vignettes and questionnaires	N = 34 38% female	Cancer/Secondary care	8–16	Level of involvement in decision-making

ᵃ Author contacted directly for participant information which was not available in published report.

3.4. Overarching themes

3.4.1. Variability in involvement preferences and experiences (n = 24): from 'It's my body' to 'Doctor knows best'

Adolescents' involvement preferences and experiences vary substantially, which can depend on the individual, timing or the nature of the information or decision type. Adolescents differ in the amount of information they would prefer to receive regarding sensitive topics, such as survival rates and prognosis in cancer treatment [58]. Many report not wanting too much information when they are feeling acutely ill or too soon after diagnosis [38,43,46,51,55]. Adolescents generally do not want to be involved in decision-making when feeling unwell, and become dependent on their parents to communicate with HCPs for them [38,45]. Relationship with and support of parents and HCPs, including trust, is often reported to effect experiences of involvement in decision-making [36,45,46,55]. Furthermore, adolescents report that with increased familiarity with HCPs they were able to become more assertive about treatment preferences [37].

The preferred level of information and decision involvement is reported to evolve over time [33,56], adolescents report wanting more information when they feel ready [51] and decision-making involvement increases as more information is obtained [45].

Adolescents also state they would prefer more involvement as they get older [49]. Age may influence involvement preferences, although this difference was normally only noted with younger adolescents [33,45,46]. Adolescents under 11 years generally do not want the responsibility of being involved in decisions, and are satisfied with others making decisions for them, whereas those over 11 years report feeling frustrated when they are not involved [37]. However, some studies found that age had no effect on involvement preferences or experiences [33,39,48,56].

Decisions are often categorised by adolescents as small or serious. Studies report that nearly all adolescents want and have input into smaller decisions such as medication administration or appointment scheduling [33–35,37,38,45,47,51,52,56–58]. Some older adolescents feel they should be involved in all decisions, even if they are 'life or death' [38,47], although many state they would prefer to leave these decision to parents and HCPs [38,40,45,47,48,51,56,58]. Experiences of involvement also depend on the types of treatment decisions being made. Adolescents whose primary treatments were oral medication regimes were more involved than with other types of treatment [47]. Although most adolescents feel that they should be involved in their treatment decision-making to some degree [37,38,40,41,43,45,46,51,53,56,58], many state a preference for

Table 2
Overarching themes and exemplary quotations.

Theme and definition	Exemplary Quotations
Variability in involvement preferences and experiences Involvement preferences and experiences can vary within and between individuals, and can depend on factors such as type of decision and current health status.	'Like, small, if they were to ask you do you want tablets or medicine, yea, of course you can make them decisions, it's your body, you should decide what you want to do like.' [37] (Female, aged 13). 'In the beginning I did not care . . . . because I was so shocked. But then, after a while I realized that I have to know what I have and what is going on. And then I started to listen again.' [51] (Male, aged 13–15). 'I think that depends on the situation. Like for how much the decision will impact or affect me and how much it will impact or affect them [parents].' [56] (Male, aged 17 with cancer).
Power dynamics and involvement in the decision-making process Adolescents feel that it is their right to be involved, and would like to be able to choose their level of involvement. However, they perceive parents and health professionals as having this control, and look to them to support and encourage their involvement.	'I think decisions are made most of the times before they come to me like the medicine and everything like, all the . . . they have already decided what to do before they come to me and ask me.' [37]. (Male, aged 18). 'They don't explain everything. The first time I was getting it, I didn't know what it was. He didn't say it when I was there. He said it to Mam behind the curtains. I was upset because I don't know what it's for or anything like that . . . I wouldn't have the guts to say anything, he comes across as a very intimidating man.' [37] [Female, aged 17]. 'They just tell you, they'd use big words and I wouldn't be able to understand them and then I'd ask my father what did they mean and he wouldn't really tell me. . . . . . if the doctor is talking for nearly 15 min or so and your father only tells you a couple of seconds then there has to be more in the story. It makes you kind a worried.' [37] (Male, aged 11 with cancer). 'He could have told me what he possibly thought it was. What he thinks they'll need to do. He could have told me anything more because it was almost like I was sat dead on the bed. He was talking to my mum, and that, but he could have been talking to me.' [47] (male aged 13–16).
Mismatch between involvement preferences and experiences Adolescents report a disparity between their preferences and experiences, which can cause anxiety, and feelings of being unvalued and excluded.	'If they at least told me, I think I would feel a little better about why I'm taking this medicine . . . I think I'd feel more comfortable if I got to talk to them.' [33] (female with cystic fibrosis). 'It made me feel a bit . . . a slight bit . . . like a piece of machinery actually, they weren't actually talking to me . . . I thought hey I'm the patient here, talk to me, explain what are you going to do' [39] (Female aged 14). 'I feel real disappointed like, just disappointed because I don't feel, like I feel like I'm kind of rejected in a way.' [37] (Male, aged, 13). 'I wish maybe they would have listened to my opinion a little more' [49] (Female, aged 16 with junior idiopathic arthritis). 'I prefer to represent myself. If I forget something, it's OK for my mum to step in, but I used to get so irritated when doctors addressed my parents instead of me, with me just sitting there!' [55] (Female, aged 19 with cystic fibrosis).

taking a passive role, as they find involvement to be boring or unnecessary, and prefer to be represented by their parent who they feel would act in their best interest [37,38,43,45,47,49,51,55,58].

3.4.2. *Power dynamics and involvement in the decision-making process* (n = 26): 'Because if it's about me then I should be part of it'

Adolescents value being able to choose their level of involvement [51]. However, they generally see parents and HCPs as having this control, and look to them for validation of their role in the decision-making process [33,34,37,40,45]. Adolescents want to be taken seriously, and feel they have a right to be involved in discussions, to have been consulted on their treatment preferences, and that these preferences are viewed as important and considered during the decision [33,36–38,51–55,58]. They recognise that their needs are different from both adults and children, and prefer their care to be adapted as such [59]. Although adolescents often do not usually want to make 'big' or 'ultimate decisions', they feel they should 'have a say', and that treatment could be worse without their input [33,34,37,38,40,43,45–48,54–56,59]. Adolescents express a need for support and encouragement from others, in order to be empowered to be involved in decisions that affect their own healthcare [37,39,40,46,47,49,56,58].

HCPs and parents are seen as the gatekeepers, controlling the amount and type of information exchanged [49]. Adolescents describe their parents as buffers or interpreters, holding the power over what information is relayed between themselves and HCPs [49,55,58]. Adolescents also report that parents can hinder their understanding by withholding information or by not supporting attempts to gain information, often to avoid worry [36,37,51,55]. Most studies reveal that adolescents express a need to receive information, specifically regarding future treatment such as: length of stay in hospital, appointment times, details on treatment choices, and possible side effects [33]. This is in order for them to understand their illness and treatment in order to be involved in self-management, and to know what to expect [33,34,36–38,43–47,49,51–59].

Discussions which exclude adolescents make them feel as though they need not or should not be involved [33]. Providing information encourages involvement [33,36,37,39,45], and encouraging involvement allows adolescents to feel empowered and validated; as a 13-year old remarked: 'they thought I was responsible enough to make a decision and I was' [33]. Adolescents state that being provided with this type of information should be a 'normal thing to do', that it is their body and their right to know and be involved [37,38,40,41,43,45,46,51,53,56,58]. Adolescents feel they cannot be involved when they do not understand [37]. Ellis et al. [41] found that the majority of adolescent patients with partial or inadequate understanding of their diagnosis felt little or no control over their treatment decision, which was not true of those who indicate complete understanding. Language is also related to control; technical jargon is described as is confusing, and can be seen as used to exert power and limit involvement [36,37,43,46,56,58]. From accounts of adolescents' experiences, Knapp et al. [47] identified lack of information about the future, poor understanding of diagnosis and/or treatment, and lack of choice between treatment options as the main barriers to involvement. Many adolescents, especially those with life limiting conditions, also state they had no control over decisions due to lack of options, that treatment 'has to be done' [33,35,37,38,40,45,47,53,58].

Reported benefits of discussion and decision-making involvement include greater self-efficacy lower decisional conflict, feeling happier, less scared and more satisfied with decisions as well as increased appointment attendance [35,39,42,45,49]. Being part of treatment discussions provides an opportunity for young people to influence their situation by learning or applying self-management

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skills [40]. However, adolescents feel they should not have complete decisional control [49]. They voice concern about making the wrong decision [33,35,37], and trust the HCP's expertise to 'do what's best' [33,37,38,40,43–45,47,49–51,53,54,56–58]. Concern about making the wrong decision is expressed more when there is no attempt to involve the patient in the decision-making process [34].

3.4.3. Mismatch between involvement preferences and experiences (n = 20): 'It hurts, one feels betrayed'

Adolescents appraise their positive and negative emotional, physical, coping, and knowledge responses to having their involvement preferences met (or not met) [38,46]. When adolescents receive the desired level of information regarding their condition, they report benefits such as feeling valued, happy, less anxious, and more capable of illness management [36,39,46,51,56]. They consequently report feeling prepared and less worried about undergoing operations and treatment [36]. However, adolescents often report receiving insufficient information about treatment and procedures [35,37,40,46]. Kelsey et al. [46] describe the case of an adolescent boy who experienced pain and anger after being cannulated with no explanation. Seven other studies report the emotional consequences of not receiving sufficient information or explanation, which include feelings of fear and/or frustration, as though they were forgotten and depersonalised [34,36,37,46,51–53]. Dunsmore & Quine found a significant difference between to what degree adolescents would prefer each person to be involved in treatment decisions, and the degree they actually were; nearly half feel the decisions should be a collaboration between themselves, parent and HCP, whereas a very small number perceived this to have occurred; and the majority report the HCP as making the decision alone, which was generally not seen as appropriate [40].

On the other side, what is seen as too much involvement, such as receiving overly detailed information, is also reported to induce stress. Many adolescents want limited exposure to details about their condition that could be worrying and/or burdensome, which they feel they may not be able to remember [37,43–45,47,51,58,59]. Adolescents sometimes experience distress from the pressure of being involved in decision-making, particularly when their treatment preferences do not coincide with those of their parents [51]. Studies which compared adolescent decisions and the factors affecting their choices, such as influences and values, with those of their parents frequently found disagreement between the two parties [33,37,38,40,48,50]. This incongruity increases significantly with patient age [48]. Parents and adolescents also report symptom severity and overall wellbeing differently [37].

Adolescents report feeling annoyed when HCPs address their parents as though they were not in the room [36,40,44,46,56,58]. They feel excluded from discussions and ignored, with questions and explanation directed only at parents [33,45,47]. They report HCPs requesting to speak to parents alone, which caused worry about a poor prognosis [37,45,51]. Some adolescents observed that HCPs would ask them questions which they felt were 'tokenistic', or in turn ask the parents the same question, which made them feel as though their responses were not valued [36,37]. Adolescents report feeling excluded from the decision-making process or that their treatment preferences were not considered [37]. They also feel that parents inhibit attempts to participate by withholding information, or answering questions on their behalf [37]. At times, adolescents report that they are not as involved as they would prefer because they feel rushed during consultations, and fear they may inconvenience HCPs by querying decisions or asking for more information [37]. When adolescents feel uninvolved in discussions and decisions, many report negative emotions such as feeling powerless, rejected, disappointed, confused, angry, and betrayed [33,37,45–47,51].

4. Discussion and conclusion

4.1. Discussion

Developing an understanding of adolescent preferences and experiences in relation to involvement in healthcare discussions and decision-making is essential in order to improve healthcare delivery and to support participation in SDM. Although studies were diverse in terms of design and samples, the results were comparable, which allowed for the development of overarching themes.

Preferences between and within each individual can vary, and evolve over time. Preferences can depend on decision type and current health status. These findings reflect previous research with adolescents and adults with LTCs [60,61], and highlight the need for HCPs to take an individual and flexible approach to involvement. Involvement preferences commonly go unmet, which adversely affect adolescent well-being, and their perceived ability to manage their condition.

Findings reveal that adolescents often feel they lack sufficient knowledge to be involved in decisions about their healthcare, and frequently report that there is no real choice. Elwyn et al's. [62,63] model of SDM iterates that the patients' understanding that treatment options exist, and how patient involvement is of value to the decision-making process, is the first step in the process. Provision of adequate information regarding diagnosis and treatment options, and ensuring patient understanding of the information has been documented as one of the essential elements of SDM [16]. However, it has been suggested that provision of information, or knowledge alone, is not necessarily enough to promote involvement in SDM [64]. Patients also need to be provided the opportunity to participate, and have confidence in their own knowledge and ability to be involved in the decision-making process.

The core finding that adolescents exert little control over their level of involvement is in line with previous research on children's participation in consultations and decision-making within the healthcare setting [19]. Adolescents look to others to validate and encourage involvement. Support and guidance from others has been well documented as a motivator for adolescent behaviour [65,66]. A large percentage of HCPs indicate that SDM was their usual approach to decisions with adolescents with LTCs [67], although other studies report otherwise [19,68]. Adolescents with LTCs often feel ignored or left out of discussions, which gives them the impression that their views are not important. They are often delegated a passive role during consultations, which does not represent the role they need to play in self-management. However, they generally feel they should be involved to some degree.

Parents of children with LTCs expect to participate in SDM [69]. They can find it difficult to relinquish control over their child's LTC for fear of poor health outcomes [70]. Lack of parental support for their child's involvement, and attempt to control the information the adolescent receives may be also attributed to parents' protectiveness [61,71]. This can be particularly troublesome as parents' treatment choices and values do not always coincide with those of their child [48]. Interventions which support SDM have been found to increase values congruence between child and parent, as well as child satisfaction with the decision-making process [72]. When adolescents do not participate in the discussion, important input that can contribute to the formation of a suitable self-management plan, which is concordant with patient values, is not being considered. The 'three-talk'

model for SDM includes 'deliberation', which outlines the importance of exploring patients' reactions to the information regarding their options in line with their own values and preferences [62,63].

One of the strengths of this review is the inclusion of qualitative, quantitative and mixed-methods research. By acknowledging research from a variety of methodological approaches, a more complete overview of the current evidence can be provided. This review was conducted according to recognised systematic review standards [73]. By only including adolescent generated data in the narrative synthesis, this review attempts to tell the story of the adolescent from their perspective, which is often underrepresented in SDM research in paediatrics.

Due to the limited literature available, studies with some non-adolescent and acutely ill participant samples were also included, which can cause difficulty in ascertaining the studies' representativeness of adolescents with LTCs in general. However, there were no distinct differences in the findings of the papers which also include participants with acute illness. Further research is needed to establish whether these findings would be consistent for all adolescents with a variety of conditions. The nature of the research methods produced largely retrospective accounts of experiences which took place weeks, month, even years prior to the study.

Ten of the 27 reports included a sample of adolescents with cancer. Unlike many LTCs, cancer has the possibility of being cured, and the focus is therefore generally on curative as opposed to management decision-making. The seriousness of the condition and, consequently, the nature of the clinical decisions involved, perhaps decreases the likelihood of clinical equipoise and may lessen opportunity for patient involvement in SDM. Although other studies include a sample of participants with various LTCs, only one [33] compared involvement level between the two conditions. In this study, participants who had a condition with less serious outcome possibilities report having more involvement than those with a potentially life-limiting condition [33]. Although this particular study had a small sample size, findings that show an association between a more serious prognosis and less patient involvement in decision-making have been reported elsewhere [74]. The lack of comparisons, and variability of LTCs across the studies included in this review limits the ability to make generalisations about all adolescents with LTCs. Further research is necessary to establish whether a connection between adolescent preferences/experiences and LTC characteristics, such as seriousness of complications, exists. Finally, due to limited resources, only English language articles were included in the synthesis.

4.2. Conclusion

Failure to involve adolescents in the decision-making process can cause feelings of exclusion and neglect. However, striving to make them fully informed and involved may also be counter to their preferred (often 'passive') way of being involved in decisions, which in turn, may itself trigger anxiety and distress. Adolescents' involvement preferences vary within and between individuals. Communication of treatment option information, as well as engaging patients in discussions which allow them to express and understand the benefits of articulating individual treatment preferences can prepare them for involvement in a shared decision. Many variables can influence the SDM process, particularly the role of the parent. Future research should further explore what may motivate or hinder adolescent participation in SDM, as well as possible reasons for the mismatch between adolescent preferences and experiences in order for issues to be addressed and SDM involvement to be adequately supported.

4.3. Practical implications

Findings suggest that parents and HCPs may be limiting adolescent involvement by withholding information, and not providing opportunities. Adolescents report a high level of trust in HCP expertise, and may not acknowledge their own capability and potential contribution to the decision-making process. Current recommendations state that adolescents should be informed as fully as their developmental level allows, as soon as possible, and that involvement in discussions and decision-making should be encouraged and supported [75]. Research shows that adolescents benefit from SDM, and it can improve their wellbeing [17].

Although HCPs report using SDM with adolescents with LTCs, it was found that they often provide more detailed information about their preferred option with less information about other options, and minimal elicitation of preferences or treatment goals [67,68]. Further skills training for HCPs could reinforce the delivery of SDM in line with current models [62,63]. In adult care, current SDM training courses for HCPs vary widely in delivery, and evidence of their effectiveness is sparse [76]. It is suggested that providing HCPs with learning materials and decision aids would be helpful [76]. Decision aids have been found to improve patient knowledge and reduce passivity in the decision-making process [77]. However, little is known about the use of decision aids in a paediatric setting. Coyne et al. [78] set out to identify SDM interventions for young people with cancer, and retrieved no results. They suggest that educational interventions aimed at increasing HCPs' awareness of young people's need for inclusion in the decision-making process could be useful. They also suggest that young people's preferences for how they want to be involved in the decision-making process should be assessed.

Adopting a flexible and individualised approach allows adolescents to participate in a way the fits with their preferences, needs and values. Striving to involve adolescents with LTCs beyond their preferences can lead to distress and confusion [61]. Adolescents might be asserting control by opting out of involvement [61], however, effective SDM involves fully informing patients about what involvement means, and why their contribution of values and preferences for treatment are important [62,63]. SDM may be particularly important during adolescence, as this is a time when children are sensitive to authoritarian treatment [79]. These patients are at a critical time where they will be transitioning, or already have transitioned to adult services where encouraging and supporting communication and involvement is crucial [80]. In future, the parent may not always be a part of the consultation. Interventions which prepare and support involvement of adolescents with LTCs in SDM could be useful to promote and encourage active participation and improve care.

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Original article

"I'd Like to Have More of a Say Because It's My Body": Adolescents' Perceptions Around Barriers and Facilitators to Shared Decision-Making

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ABSTRACT

Purpose: Adolescents living with long-term conditions (LTCs) often feel as though they are left out of discussions and decisions with healthcare professionals, which can give them the impression that their views are not important. Research around decision-making during clinical encounters often fails to represent adolescents' perspectives. This study explores adolescents' perceptions and experiences, focusing on identifying the perceived barriers to, and facilitators for, their involvement in shared decision-making (SDM).

Methods: Nineteen adolescents (aged 13–19 years) with LTCs were recruited from endocrinology, rheumatology, neurology, and nephrology clinics. Participatory qualitative interviews were conducted using life grids and pie charts, and transcripts were analyzed thematically.

Results: Four overarching themes and nine sub-themes were identified which describe barriers and facilitators around SDM. Adolescents need to feel, as though their involvement is supported by parents and healthcare professionals, that their contribution to the decision-making process is important and will yield a positive outcome. Adolescents often feel it is their right to be involved in decisions that affect them but also feel as though the adults' contributions to the decisions are considered more valuable. Adolescents need to feel capable of being involved, in terms of being able to understand and process information about the available options and ask appropriate questions.

Conclusions: This work highlights a number of ways SDM can be facilitated between healthcare practitioners and adolescents with LTCs. Identifying the needs of adolescents with LTCs is necessary for optimizing the SDM process and to support them during healthcare consultations.

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IMPLICATIONS AND CONTRIBUTION

Adolescents describe a number of barriers and enablers around their involvement in shared decision-making. These include having favorable context, positive evaluation, feeling able and ready, and having some sense of actual control alongside their developing identity and perceptions of what is "normal." The findings will assist in development of interventions aimed at improving shared decision-making with this population through identification of components that are necessary, feasible, and salient.

Adolescents with long-term conditions (LTCs) often feel as though they are left out of discussions and decisions with

healthcare professionals (HCPs), which can give them the impression that their views are not important [1]. Current recommendations emphasize the importance of involving adolescents in healthcare decisions and state that health service provision should be a partnership between the HCPs, young persons, and their families [2,3]. Moreover, patient involvement in decision-making has been identified as a key indicator of

adolescent healthcare quality [4]. Shared decision-making (SDM) has the potential to allow adolescents with LTCs to evaluate the benefits and risks of various healthcare options while enabling a shared understanding of preferences and possible issues, such as difficulties performing self-management tasks or managing side effects [5,6]. SDM may increase adherence to self-management plans [7,8], which can be particularly important during adolescence when self-management and health outcomes of patients with LTCs have been found to decline [9–11]. In addition, adolescent involvement in healthcare decisions is associated with a better understanding of their health condition and treatment [12].

Nevertheless, SDM does not occur consistently in clinical encounters, and adolescents with LTCs often act as bystanders [13,14]. Furthermore, previous literature examining these encounters often focus on parents' and HCPs' experiences, omitting the young person's narrative [1,15]. Therefore, the purpose of this study was to explore adolescents' perceptions and experiences, focusing on identifying the perceived barriers to, and facilitators for, their involvement in SDM.

Methods

Participants and recruitment

A sample of 19 adolescents aged between 13 and 19 years (mean + standard deviation = 16 ± 1.9) was recruited from young adult (transitional) or pediatric neurology, endocrinology, nephrology, or rheumatology clinics in South Wales (Table 1). Patients attending these clinics tend to have LTCs, which have distinct characteristics from one another. However, the conditions often persist into adulthood, affect the patients' lives substantially, and have a range of management options, allowing for the ideal environment for SDM. Potential participants were purposefully identified by members of their clinical team and approached in attempt to obtain an even distribution of ages, genders, and LTCs. Information packs were distributed to eligible adolescents containing details on how to respond if interested in participating in the study, to which 29% responded. Participants

Table 1
Recruitment summary

	Adolescents responded, N = 19	Adolescents approached, N = 66
Sex, n (%)		
Female	14 (74)	36 (55)
Male	5 (26)	30 (45)
Age range		
13–15	9 (47%)	31 (47%)
16–19	10 (53%)	35 (53%)
Mean ± SD	16 ± 1.9	16 ± 2.2
Time elapsed since diagnosis (y)		
Range	1–18	-
Mean + SD	7.2 ± 4.8	
Recruitment clinic, n (%)		
Neurology	6 (31)	20 (30)
Endocrinology	7 (37)	20 (30)
Rheumatology	2 (11)	8 (12)
Nephrology	4 (21)	18 (27)
Ethnicity, n (%)		
White	15 (79)	-
South Asian	3 (16)	
Black	1 (5)	

provided informed consent, and parental consent was obtained for participants aged <16 years. Interviews took place at University Hospital Wales, the participants' homes, or a quiet café, away from other customers or employees. Parents requested to be present during the interviews on two occasions. Respondents received a £20 voucher as a token of appreciation for their participation. Ethical approval was obtained from the National Health Service Research Ethics Committee and Cardiff and Vale University Health Board Research and Development Office.

Participatory interviews

Participatory interviews were conducted by the first author (A.J.), an experienced researcher trained in qualitative methods, to explore the adolescents' narratives to identify possible barriers and facilitators to SDM. Respondents were first asked to complete a life grid [16] with important events surrounding their health condition and doctors' visits. Participants were asked to describe the events in the grid and prompted to expand on the events by the interviewer asking questions. Where healthcare decisions were mentioned, participants were asked to complete pie charts [17], indicating both the real and desired roles of those involved in the decisions (Figure 1, Table 2). Possible reasons for discrepancies between the real and desired roles were explored. A follow-up semistructured interview schedule was also derived from the findings of our systematic review [1] (Table 3). Data collection methods were piloted with two male adolescents.

Qualitative analysis

Interviews were audio recorded and transcribed (A.J.). We then conducted a thematic analysis using Braun and Clarke's [18] approach. By following the six phases of coding and theme development, we developed four themes in response to our aims. This process involved the first author repeatedly reading the transcripts and coding the entire data set, which resulted in a demarcation of common themes. Provisional themes were reviewed and discussed by two authors (A.J. and N.J.W.), and further refinement of the coding and analysis was undertaken until the salient patterns repeated across and within transcripts were identified and agreed on [18]. Initial coding and theme development began after the first 14 interviews. The five subsequent interviews were coded, and no new themes were identified. It was therefore determined that inductive thematic saturation had been achieved [19]. Another author (D.H.-H.) then double coded the transcripts, and the outcome of proceeding discussions resulted in modification of subtheme names and an additional subtheme. Pseudonyms were used, and potentially identifying minor details were changed for confidentiality purposes. Data were managed using NVivo 11 qualitative data analysis software (NVivo 11 for Windows, Version 11.2.1.616, QSR International Pty Ltd, Melbourne, Australia) [20].

Results

Interviews ranged from 20:04 to 57:25 (mean+ standard deviation = 35:35 ± 10:06, median = 34:31) minutes. Some participants freely provided detailed information using the life grid, whereas others were more hesitant, even with prompting. The presence of parents in the room (n = 2) did not appear to affect the participants' willingness to disclose. Themes identified

Adolescents' perception of roles in a healthcare decision	Adolescents' desired roles in a healthcare decision	Adolescents' explanation of "real" versus "ideal" roles
		"I guess cuz like the neurologist said I should, my parents said to give it another go and my epilepsy was so bad I had to give it a try again, even if I didn't want to I had to try." (Female, aged 18, neurology, 15 years)
		"Maybe equal, maybe not my parents so much. I'm old enough now, like yeah, they don't need a say, they did before but that should change. I should have a say, and understand why and what I'm taking, you know?" (Male, aged 13, endocrinology, 13 years)
		"Not everything the doctor says is clear like for us to understand so you know, having a say or asking questions may, like, make us understand more. So I can know what I have to do or if I was confused about something that, we should have our own say." (Male, aged 19, nephrology, 10 years)
		"Because obviously I was just diagnosed, and they were like: "if you want to try it, you can try it, and then if you don't like it, you don't have to go on with it". I tried it for about maybe two weeks." (Female, aged 15, endocrinology, 5 years)
		"I would have made the decision myself anyway cuz I knew at the time I wanted to go off it, that's what I had in my head. Um I guess I could have let them have a little say in it but it's just what I wanted to do so I, I would have allowed them like a quarter, not even that, because I at the time, I was determined I didn't want to be on any medication, so yeah" (Female, nephrology, aged 18, 18 years)

Figure 1. Pie charts allocating perceived and desired role representation of adolescents, parents, and HCPs in decision-making for specified healthcare decisions.

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Table 2
Decisions described using pie charts

Number of decisions	
Total	N = 39
Range per participant	1–3
Mean + SD	2.1 ± .7
Mode	2
Types of decisions	
Begin treatment (e.g., insulin, anticonvulsants, analgesics)	N = 15
Change type/dosage/frequency of medication	N = 11
Change method of medication administration (e.g., from insulin injections to pump)	N = 4
Lifestyle changes (e.g., diet, exercise)	N = 4
Discontinue medication	N = 3
Undergo surgery	N = 1
Participate in a clinical trial	N = 1
Adolescent role allocation: Desired versus actual involvement	
Ideal = real	N = 23 (59%)
Ideal > real	N = 14 (36%)
Ideal < real	N = 2 (5%)

from the interviews were not found to be distinct between genders, ages, or LTCs.

Many participants were able to identify explicit barriers to and/or facilitators of their involvement in SDM. They also discussed such influences more implicitly when describing their experiences with decision-making during consultations. Our analytic review process resulted in a final analytic structure of four themes and nine subthemes, which describe barriers and facilitators around SDM (Table 4). The quotations used to illustrate the themes are followed by participant gender, age, clinic recruited, and elapsed time since their diagnosis.

Interactional dynamics within the triadic relationship

The dynamics between the adolescents, parents, and HCPs strongly influence adolescent involvement in SDM.

HCPs communication approach. The way HCPs communicate with parents and the adolescents can either endorse or dismiss adolescent involvement in the decision-making process. Clinicians' behavior that invites and encourages involvement includes asking and inviting questions; speaking directly to the adolescents instead of the parents; information provision, including presenting treatment options; and providing adolescents with enough time to consider the options so that they do not feel rushed. Adolescents feel more comfortable when HCPs

communicate in a manner that is perceived as friendly, which can encourage involvement.

Sometimes it helps when the doctors are like nicer. Like when the doctors are friendly and stuff, then you feel more at ease to talk to them. Whereas if it just feels like they're bored or like, they're like really serious, it's kind of like hard to speak. [female, aged 19, Endocrinology, 6 years].

Adolescents, even those who believe they play a large role in decision-making, report being provided insufficient information surrounding treatment options, which limits their ability to be involved. Some adolescents feel that HCPs are too busy to explain their condition or treatment options in detail.

I don't feel like I've had it properly explained by the doctor, cuz obviously you've got time slots cuz more people need to come and see. They can't spend all day telling you about it. [male, aged 18, Endocrinology, 5 years]

Parental support of adolescent involvement. Participants often feel that their parents' roles in decision-making should be smaller than they actually are, and that parents should play more of a supporting role.

They [parents] should just like advise me mostly, because I know it's about me. [female, aged 14, Rheumatology, 3 years]

Parents can support involvement by filling in missed gaps of information provided by adolescents and helping adolescents to process and remember information provided by HCPs. However, adolescents often feel their parent(s) limit their involvement by not allowing them the opportunity to speak.

My mother takes over, because she thinks she can have more of a say than I do cos s she's the mother…she should just stand back and let me talk, say in my opinion. [female, aged 18, Nephrology, 18 years]

Furthermore, having parents present in the consultation can sometimes cause unwillingness to share certain information of a sensitive nature.

No offence to any parents, but having the parents out of the room is a massive relief because it just is, and if you feel confident enough to talk about it. [female, aged 15, Endocrinology, 7 years]

Power imbalance. Adolescents mostly would like a nearly even three-way split between themselves, parents, and HCPs, usually allocating slightly less of a say to parents. However, the adults (parents and HCPs) are often seen as having more influence over

Table 3
Sample semistructured interview questions

	Sample interview questions	Sample follow-up questions
1.	How have treatment options been presented to you in the past?	How do you think treatment options should be presented?
2.	What do you think your/your parent's/HCPs roles should be in decisions and discussions?	How does this compare to your actual roles?
3.	In what way do you think SDM is important?	Why or why not?
4.	What has stopped you from being more involved in SDM in the past?	How did you feel about that?
5.	What would make you want to participate in SDM in the future?	How would this make you more involved?
6.	What are important things for you to consider when being involved in SDM?	How do you express these considerations?
7.	How knowledgeable do you feel about your condition and how to manage it?	(How) would you like this to change?
8.	How comfortable do you feel asking HCPs questions?	What might make you feel more comfortable?
9.	What kind of information do you think HCPs need to know about you?	(How) do you make sure HCPs know this information?

HCP = healthcare professionals; SDM = shared decision-making.

Table 4
Themes/subthemes, their description, and exemplary quotes

Themes/Subthemes	Description	Exemplary quote
Interactional dynamics within the triadic relationship		
HCPs' communication approach	HCPs either invite or prevent SDM involvement in the way they interact with adolescents and parents.	They [HCPs] will ask you questions sometimes, but we need to be encouraged to ask questions, not just sit there and listen. But they mostly talk to my parents, they talk to my parents more than they talk to me. [female, aged 14, Rheumatology, 3 years] They [HCPs] speak to me, so I speak back. I never used to … But now they've started speaking to me, I started speaking back. [male, aged 14, Rheumatology, 11 years]
Parental support of adolescent involvement	Parents' support can facilitate involvement; however, they often inhibit involvement by "taking over" during consultations.	Probably just telling my mum to stop talking, it's difficult with her speaking all the time for me to speak as much as I think I should. I could probably ask her not to come in with me and she'd probably be ok with it. It would probably be much better cuz I could speak to him [HCP] and say like, yeah more stuff what I feel. They [HCPs] normally speak to both of us, but my mum normally is like: "Yeah, she's doing this, she's doing this, she's doing this" it's like mum, let me speak. I don't mind my mum helping if I forget something, but I liked it being able to speak myself in my appointment the other week. I prefer her to just be there to help, and me be the main person the doctor speaks to. [female, aged 15, Neurology, 5 years].
Power imbalance	Adults are often seen as having more authority over the decision-making process.	I'm just happy to sit back and let them [adults] say what they want because obviously they know better. [male, aged 13, Endocrinology, 13 years] I really didn't have much of a say in it because I was under 18 so it wasn't my decision, it was basically down to the doctor and my mum. [male, aged 19, renal, 10 years]
Expression of autonomy		
Sense of agency	Adolescents feel they "should" be involved in decisions that affect them.	It's cuz obviously it does affect me at the end of the day, so I'd like to be involved as well as the doctor cuz, I dunno, it's my condition at the end of the day. I mean, I know it's diabetes, but everyone's diabetes is different, so I probably know my own a bit better than the doctor does. Just because you know yourself, and you know what's …you need to really, specially after you've had it for a while. [female, aged 15, Endocrinology, 1 year] Well, like it's important, it's your body, you need to have a say. Of course the doctors are the experts, but you know your body. They don't know how it feels to be you and live with it, and the effects. [male, aged 14, Rheumatology, 11 years]
Sense of empowerment	Adolescents need to feel they have control over the processes. Some adolescents disengage from discussions and make decisions as a reaction to a perceived loss of control.	I understand they [doctors] have to say that, but there is times where it drags on to the point where I'm like: "Now you've said all this, I really don't want to do it, just because I'm so tired and bored of hearing it. [male, aged 13, Endocrinology, 13 years] I shoulda taken it, but it's, you're so in your own head about being like: "Nah, no thank you" that you don't do it at that time, you just pull a strop. So, yeah, so I regret that a bit, about as in like I felt in that moment I was a bit like: "Well, I get a say in this" so I'm happy about that because I said "no" I didn't follow through with whatever they told me, so it was like, can't listen to your doctor all the time, even though you should, there's moments where you just don't. [female, aged 16, Neurology, 5 years]

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Table 4
Continued

Themes/Subthemes	Description	Exemplary quotes
Belief around own ability and value of contribution		
Perceptions around involvement outcomes	How adolescents perceive possible outcomes of their involvement in SDM affects their attitudes toward being involved.	If they [patients] are involved they will know what's going on and then they can learn more [male, aged 18, Endocrinology, 5 years] Sometimes I think people don't do it because they're scared of what the outcome's gonna be if they put forward their decision. [female, aged 14, Rheumatology, 3 years]
Perceived adequacy of own knowledge and skills	Adolescents' self-efficacy around involvement in discussions and decisions influences their actual involvement.	Cuz some of my things come out like daft, I come out with daft things. Or I'll be about half way through a blooming sentence and then like I've forgotten what I'm going to say, and we've got a finish with that conversation. [female, Neurology, 2 years] Naivety. Just not knowing what, I wouldn't know what I was talking about, um the medications and stuff like that. I wouldn't know what to discuss. I don't know. [male, aged 14, Rheumatology, 11 years]
Navigating personhood identity and patienthood identities		
Endeavour for normality	Adolescents do not want to feel different, which can cause them to disengage during discussions. Contact with other young people in similar situations provides support and allows them to feel more "normal."	Also, I think would happen if people, like you know the same ages, someone a year older or uh two years older or the same age as me has like a different illness, and say they have epilepsy and I have diabetes, we can speak about the similarities to it, and the differences to it, like how it affects you cos I think speaking with someone your age, sometimes friends are not enough, and sometimes talking with a stranger, not a stranger, but talking with someone with your type of thing helps. [female, aged 15, Endocrinology, 7 years] dunno maybe you do feel like it's a little bit unfair like, cuz obviously like you've gotta go to school with kids that don't have it and stuff, and then it's like just a bit unfair so like then you're in that mind-set and then you just, you didn't even, you can't be bothered asking things, stuff like that. [female, aged 19, Endocrinology, 6 years]
Readiness to be involved	Adolescents need to feel ready to be involved in SDM. This usually develops over time from diagnosis. Lack of readiness can lead to avoidance and incite fearfulness.	I dunno, I just got too nervous when they were talking about it, because like a lot of people do not like going into hospital, just nervous about just having to be there and did not want to think about it. [female, aged 15, Neurology, 13 years] with this type of disease that can alter my life or whatever um and maybe just like a small amount of information at first so that, I do not know, people did not get too panicked. [female, aged 19, renal, 4 years]

HCP = healthcare professionals; SDM = shared decision-making.

the decision-making process, and their contribution may be more valuable. The perceived power imbalance between the adolescent and the adults can cause adolescents to feel that the others have and possibly should have more authority over decisions.

> They [HCPs] are generally just talking to the adults, looking at the adults and not me... I know why they do it mostly cuz, you know, they're adults, they get the most attention really. [female, aged 14, Rheumatology, 3 years]

This can cause adolescents to feel as though they are not "allowed" to be involved in the decision-making. Furthermore, consultations are sometimes viewed as a time when adolescents are reprimanded by adults for less favorable self-management results, such as high HbA1c levels, which can cause feelings of guilt and reluctance to engage.

Expression of autonomy

Overall, adolescents with LTCs react positively toward the concept of SDM. They value and want a sense of control over their lives and decisions that affect them.

Sense of agency. Adolescents express ownership over their bodies and their health. They often feel that they should be involved, and it is their right to be included in the decision-making process, which facilitates SDM.

Um I think you should be allowed to make any decision you want really. Because it's you as a person, it's not them, they're not going through it. [female, aged 16, Neurology, for 5 years]

Adolescents state that they know about their own lives and bodies better than anyone else and, therefore, feel that it is vital that they have a say in decisions which are relevant to them. However, many adolescents acknowledge that they are not and have not been as involved in the decision-making process as they should be.

I dunno, I suppose it's my body, and I have to deal with the consequences so I should probably have more of a say. [male, aged 17, Endocrinology, 2 years]

Sense of empowerment. When adolescents feel they have control over what is happening to them, they react positively toward being involved in discussions and decisions, which can facilitate SDM.

I really felt like I was being in control of myself then. And I could give my opinion on what was going on. [female, aged 15, Neurology, 6 years]

On the other hand, a number of adolescents spoke of their reactions to feelings of powerlessness and perceived loss of control. This can lead them to refusing to engage in discussions, sometimes taking complete control over a decision as a consequence.

when I come off medication for like a year, that was all my own decision, and they [HCPs and parents] didn't really have an option, I did not let them have an option cuz I was like 'no I don't wanna be on that' I just like refused it. [female, aged 18, Neurology, 15 years]

Reports of autonomous decision-making on the part of the adolescent were the only decisions for which participants indicated that they should have had a smaller role.

Belief around own ability and value of contribution

This theme focuses on adolescents' evaluation of their involvement in different aspects of SDM. The concept of a "good" or "right" decision often arose in discussion.

Perceptions around involvement outcomes. Treatment preferences and values vary between individuals. Some adolescents identify the importance of adding their input to discussions and decisions to find the treatment that best suits them and to best understand what is happening to them.

I think if I was more involved in the decision, I could take more ownership over my self-management. [male, aged 17, Nephrology, 2 years]

However, adolescents do not always acknowledge the importance or benefits of their contribution. They may not feel interested or motivated to be involved and often believe that the doctors hold the knowledge about what is best for them.

You just really, just have to go along with [treatment] because the doctor's right, end of story really. [male, aged 19, Nephrology, 10 years]

Perceived adequacy of own knowledge and skills. Participants spoke about self-efficacy regarding a number of aspects of involvement, including their knowledge and understanding around their condition and management options, asking questions, remembering information, discussion involvement, and making a "good" decision. Insufficient understanding surrounding their condition and treatment options is the most commonly mentioned barrier to SDM. There was no apparent relationship between self-efficacy and participants' age at the time of interview; however, many expressed that their confidence increased as they gained more experience living with their condition, which allowed them to become more involved in discussions and decision-making.

I dunno, I think just cuz I'm older, and at the time I didn't really know very much about diabetes, so I kind of didn't feel like I could say what I wanted cuz I didn't want it to be like a little bit wrong or something silly, if that makes sense. Now I feel just a little bit more confident because like obviously I've had it for years, so I kind of do know. [female, aged 19, Endocrinology, 6 years]

Fear of saying something "wrong" or asking a "stupid" question is a common sentiment, which prevents adolescents from being involved.

Sometimes I don't understand what's going on, but I feel like if I ask a question, I might sound kind of stupid, um they're like kind of basic questions, you know like normal questions, yeah stuff like that. Maybe I shouldn't ask them because they're too basic. [female, aged 15 with epilepsy for 6 years].

Perceived capability in their ability to remember, both what to say and what has been said also influences involvement.

My memory is horrendous. I prefer my mum to say it so I do not miss anything out. [female, aged 16, Neurology, 6 years].

Navigating personhood and patienthood identities

This theme represents the conflict of identity between patient versus self that adolescents with LTCs can experience. This conflict can cause them to go between accepting their LTC and disconnecting from or avoiding the fact that they have the condition. This can lead to disengagement from healthcare discussions and decisions.

Endeavour for normality. The importance of trying to maintain as normal a life as possible was highlighted by many of the adolescents in the interviews. Adolescents often compare their current lives to before diagnosis and strive to regain that sense of normality. Some adolescents acknowledge that involvement in decision-making can assist with the selection of a treatment plan, which best helps them to regain normality, such as changing from insulin injections to an insulin pump. Feeling as though they can be "normal" teenagers alongside their LTC can result in acceptance of the condition and allows them to engage and be involved in SDM. However, adolescents might not want to be involved in discussions and decisions during consultations because they prefer not to be reminded of having a condition, which sets them apart from others. Having contact with other adolescents with LTCs can help adolescents maintain feelings of normalcy:

If you're meeting people who have got similar health conditions to you, or experience health conditions in general, you can get

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out with them, you can talk with them, see how they're feeling, what they've experienced, and I think that's a really good way to also influence you to um, you know, talk about your decisions because you know then what other people have done, and what they've been through, knowing that you're not alone. [female, aged 18, Nephrology, 2 years].

Readiness to be involved. At the time of diagnosis, adolescents can find it difficult to process information, and prefer less involvement.

you're shocked cuz you've obviously just been diagnosed and then it's hard to take in so much information because it just feels like it's been like forced on you, obviously you've gotta learn it, but there's just a lot to take in at that time… now I feel just a little bit more confident because like obviously I've had it for years. [female, aged 15, Endocrinology, 1 year]

Apart from very soon after being diagnosed, all adolescents express a desire to be involved in decisions to some extent. Acceptance of their condition is necessary for adolescents to feel ready and is more likely to be reached as they gain more experience living with the condition. Adolescents need to feel emotionally ready to receive certain information and be involved in certain discussions and decisions. Involvement when adolescents do not feel ready can lead to avoidance and fearfulness.

I dunno, I just got too nervous when they were talking about it… and didn't want to think about it. [female, aged 15, Nephrology, 13 years]

Discussion

This study provides insight into adolescents' perceptions around decision-making involvement by focusing on their lived experiences during consultations. The use of pie charts is a method that has been used successfully in previous studies exploring adolescents' roles and preferences in the decision-making process [17,21]. However, this study differs in its focus on possible reasons for the discrepancies between the real and desired roles and potential enablers of involvement.

Adolescent-reported barriers and facilitators to SDM relate to interactional influences and evaluations around SDM in line with their self-efficacy and sense of self. Our results add to the growing evidence base identifying the significance of the relationship between the HCP and adolescent patient and the importance of reducing the perceived power imbalance [22,23]. This is also a known barrier to SDM in adult populations receiving chronic care, and patients often undervalue the contribution of their own personal preferences to decision-making, rather than that of HCPs technical knowledge [24,25]. In pediatrics, the triadic relationship adds an additional complication, where parents can be perceived to block SDM. Parents can find it challenging to relinquish control over their child's LTC for fear of poor health outcomes and require clarification on their role from HCPs [26]. HCPs commonly report parents' emotional state as a barrier to SDM [27]. Although adolescents value their parents' support in the decision-making process, they often prefer parents to have a lesser role. Adolescents with LTCs would like the chance to see HCPs alone to discuss sensitive matters but are rarely offered this opportunity [1,28]. Parents worry about not receiving important information about their child's health, which they value over patient confidentiality

[28]. Discourse needs to take place between the three parties around adolescent confidentiality, which has the potential to empower and improve adolescent autonomy, and can allow them the opportunity to be forthcoming about potentially risky behaviors [28,29]. HCP training on how to foster parents to support their child's autonomy and involvement could be instrumental.

In line with previous findings [17], nearly all the adolescent participants indicate a desire for the same or greater involvement in the decision-making process, particularly as they gain more experience with their condition. HCPs' behavior can improve adolescent involvement in SDM by ensuring they speak to patients directly, providing sufficient information about options, inviting questions, and making it clear that they want them to be involved. Being invited to participate has been previously identified by adolescents as an important facilitator for SDM [27]. HCP friendliness and direct communication are seen to be essential in adolescent healthcare delivery [12]. HCPs also need to be mindful of other communication factors (e.g., tone of voice) when communicating with adolescents [12], as adolescents can fear judgement from HCPs, which has been previously reported to induce stress and affect disclosure [30].

Adolescents need to feel ready to try SDM and feel it aligns with their developing identity and sense of normality. Receiving a diagnosis of an LTC can change one's self-perception, triggering a multitude of emotions such as shock, anxiety, anger, fear, and despair [31,32]. Adolescents recognize that their involvement preferences change, and it is vital that they feel they have control over this, as failure to meet involvement preferences can be detrimental to their well-being [1]. In line with the core elements of SDM and patient-centered care, clinical strategies that elicit adolescents' context and perspective, provide support, and offer tailored guidance have been previously identified by adolescents as enabling their behavior to change [33]. Adolescents can vacillate between acceptance and avoidance of their condition, which affects the extent they engage during consultations. Adolescents with LTCs feel set apart from their peers socially and physically, but strive to live a normal life [34,35]. Having contact and support from other peers with an LTC is important in making adolescents feel normal, and peers can be seen as a resource to learn about LTC experiences and involvement [34]. When SDM is seen as normative behavior, it can encourage adolescents to be involved. Furthermore, SDM can allow for the selection of options which are most congruent with adolescents' values, preferences, and sense of normality [5].

The adolescent participants often relay contradictory perceptions around their roles and involvement. They grapple with feeling that it is their right, and they should be involved in decisions that affect them, but that doctors are the experts and are more able to make the "right" decisions. This battle can make it difficult for adolescents to identify their role during consultations. The concern of adolescents with LTCs around making a "wrong" healthcare decision has been reported before [36,37]. HCPs could cultivate adolescents' understanding of the SDM processes, which emphasize the importance of patient expertise, and help adolescents to view SDM as a balance, which is in line with their own values and beliefs.

Limitations

Although we attempted to recruit an equal number of male and female participants, significantly larger number of responders were female. This responder gender bias has been

reported in other qualitative studies with adolescents with LTCs [38,39]. However, themes identified from the interviews were not found to be distinct between male and female participants. With a low response rate, this study may have limited generalizability, and those who are more willing to be involved in qualitative health research may also take a more proactive approach to involvement in healthcare decisions. However, there was a range of responsiveness during the interviews, which is reflected in the duration of interview recordings. Despite these limitations, there are considerable strengths to the study. The use of participatory methods proved effective in eliciting and representing young people's perspectives and biographical narratives. The life grids afforded the respondents a degree of control over disclosure of sensitive issues. In previous studies, this has been found to alter traditional interview dynamics in attempt to address the potential issue of perceived power imbalance between the researcher and participant [16,40]. This may be particularly important for adolescents, where perceived power and control are strong influencers of involvement.

Developing an understanding of barriers and facilitators to SDM as perceived by adolescents with LTCs is essential to improve long-term healthcare delivery, and encourage and support SDM involvement. The data presented could be used to inform the development of interventions aimed at HCPs, parents and adolescents with LTCs. Finally, although strategies can be developed to encourage and support adolescents' involvement in SDM, it is crucial that even the decisions around the extent of involvement are also shared.

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Appendix 3. Chapter 4 – Study documentation including: ethical approval, information sheets, invitation letters, consent/assent forms and reply forms

3.1 NHS Research Ethics Committee Approvals and Amendments

NHS
Health Research Authority

London - London Bridge Research Ethics Committee
Skipton House
80 London Road
London
SE1 6LH

Telephone: 020 797 22567

> Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

02 November 2017

Miss Amber Jordan
Cardiff University, School of Medicine
5th floor, Neuadd Meirionydd, Heath Park
Cardiff
CF144XN

Dear Miss Jordan

Study title:	The development of an intervention aimed at addressing the perceived barriers to and facilitators of the participation of adolescents with long-term conditions in shared decision making about their healthcare.
REC reference:	17/LO/1694
Protocol number:	SPON1622-17
IRAS project ID:	232192

Thank you for your letter, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

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Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with

prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance]	1	15 July 2017
Interview schedules or topic guides for participants [Phase 1 Interview Schedule]	2	19 October 2017
Interview schedules or topic guides for participants [Phase 1 Interview Schedule]	2	25 October 2017
IRAS Application Form [IRAS_Form_26102017]		26 October 2017
Letter from sponsor [Sponsor Letter]	1	16 August 2017
Other [Phase 1 Assent: 12-15]	1	15 August 2017
Other [Phase 2 Assent: 12-15]	1	15 August 2017
Other [Phase 1 invitation: Parent]	1	15 August 2017
Other [Phase 2 invitation: 16-19 year]	1	15 August 2017
Other [Phase 2 invitation: parent]	1	15 August 2017
Other [Phase 1 reply form: 16-19]	1	15 August 2017
Other [Phase 1 Reply form: Parent]	1	15 August 2017
Other [phase 2 reply form: 16-19]	1	15 August 2017
Other [Phase 2 reply: parent]	1	15 August 2017
Other [PIS Phase 1 participants 12-15]	2	19 October 2017
Other [PIS Phase 1 Parents]	2	19 October 2017
Other [PIS Phase 2 participants 16-19]	2	19 October 2017
Other [PIS Phase 2 participants 12-15]	2	19 October 2017
Other [PIS Phase 2 HCPs]	2	19 October 2017
Other [PIS Phase 2 Parents]	2	19 October 2017
Other [Phase 1 consent: parents]	2	19 October 2017
Other [Phase 2 Consent: 16-19]	2	19 October 2017
Other [Phase 2 consent: parents]	2	19 October 2017
Other [Phase 2 consent: HCPs]	2	19 October 2017
Other [Phase 2 Interview Schedule]	2	19 October 2017
Other [Phase 2 Interview Schedule HCPs]	2	25 October 2017

Other [PIS Phase 1 Parents]	2	19 October 2017
Other [PIS Phase 2 participants 16-19]	2	19 October 2017
Other [PIS Phase 2 HCPs]	2	19 October 2017
Other [Phase 1 consent: parents]	2	19 October 2017
Other [Phase 2 Consent: 16-19]	2	19 October 2017
Other [Phase 2 consent: parents]	2	19 October 2017
Other [Phase 2 consent: HCPs]	2	19 October 2017
Other [Phase 2 Interview Schedule]	2	25 October 2015
Other [Covering Letter]	1	31 October 2017
Participant consent form [Phase 1 Consent: 16-19 years]	2	19 October 2017
Participant consent form [Phase 1 Consent: 16-19 years]	2	19 October 2017
Participant information sheet (PIS) [Phase 1: 16-19 years]	2	19 October 2017
Participant information sheet (PIS) [Phase 1: 16-19 years]	2	19 October 2017
Referee's report or other scientific critique report [Supervisor Review]	1	15 August 2017
Research protocol or project proposal [Protocol]	2	19 October 2017
Research protocol or project proposal [Protocol]	2	19 October 2017
Summary CV for Chief Investigator (CI) [CV]	1	12 September 2017
Summary CV for student [Student CV]	1	12 September 2017
Summary CV for supervisor (student research) [Supervisor CV]	1	12 September 2017

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the Research Ethics

Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance

We are pleased to welcome researchers and R & D staff at our RES Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

17/LO/1694	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

pp *Dherodie*
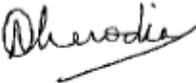
Professor David Bartlett
Chair

Email: nrescommittee.london-londonbridge@nhs.net

Enclosures:	*"After ethical review – guidance for researchers"*
Copy to:	Mr Chris Shaw
	Mrs Lee Hathaway, Cardiff and Vale UHB

London - London Bridge Research Ethics Committee

Skipton House
80 London Road
London
SE1 6LH

Tel: 020 7104 8222
Fax: 020 7104 8222

09 March 2018

Miss Amber Jordan
Cardiff University, School of Medicine
5th floor, Neuadd Meirionydd, Heath Park
Cardiff
CF144XN

Dear Miss Jordan

Study title:	The development of an intervention aimed at addressing the perceived barriers to and facilitators of the participation of adolescents with long-term conditions in shared decision making about their healthcare.
REC reference:	17/LO/1694
Protocol number:	SPON1622-17
Amendment number:	1
Amendment date:	12 February 2018
IRAS project ID:	232192

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMP)	1	12 February 2018
Participant information sheet (PIS) [Phase 1 PIS - Parents.Guardians V3.0 01-02-18]	3	01 February 2018
Participant information sheet (PIS) [Phase 1 PIS - Participant 16-19 years V3.0 01-02-18]	3	01 February 2018
Participant information sheet (PIS) [Phase 1 PIS - Participants 12-15 years V3.0 01-02-18]	3	01 February 2018
Research protocol or project proposal		01 February 2018

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

17/LO/1694:	Please quote this number on all correspondence

Yours sincerely
PP:

C. Frost

Dr Michael Goggin
Chair

E-mail: nrescommittee.london-londonbridge@nhs.net

London - London Bridge Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 28 February 2018

Committee Members:

Name	Profession	Present	Notes
Dr Hilary Crowe	Student of Biomedicine at Birkbeck	Yes	
Dr Michael Goggin	Consultant Physician	Yes	

Also in attendance:

Name	Position (or reason for attending)
Mr Connor Frost	REC Manager

London - London Bridge Research Ethics Committee

21 November 2018

Miss Amber Jordan
Cardiff University, School of Medicine
5th floor, Neuadd Meirionydd, Heath Park
Cardiff
CF144XN

Dear Miss Jordan

Study title:	The development of an intervention aimed at addressing the perceived barriers to and facilitators of the participation of adolescents with long-term conditions in shared decision making about their healthcare.
REC reference:	17/LO/1694
Protocol number:	SPON1622-17
Amendment number:	V4
Amendment date:	04 October 2018
IRAS project ID:	232192

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Extract from minutes

The sub-committee attached a tracked changes for the document "Phase 2 PIS – aged 16-19".

The applicant responded by submitting the document with the requested changes.

The sub-committee attached requested changes for the document "Phase 2 Assent Form – 12-15".

The applicant responded by submitting the document with the requested changes.

The sub-committee requested that the applicant changes the protocol study summary (top of p2) so it reads, 'one-to-one interviews' **and** focus groups as it is describing the whole study.

The applicant amended the protocol summary (top of p2) to include focus groups as well as interviews.

The sub-committee asked for the Discussion Guide for the focus group. This is because the questions on page 5 of the Protocol will change since the participants are going to be asked to look at a number of 'materials' developed following the first phase.

The applicant clarified that P5 of the Protocol only refers to the first phase of the study, which only involved one-to-one interviews and is now complete. The "materials" they have developed as a result of these interviews is a booklet. The focus groups would be in phase 2 (user testing) which is described on p8. There are no real changes to the discussion guide, only that the applicant would like to go through it as a group instead of one-to one. This is described more in depth in "Phase 2 Interview Schedule - Patients".

The sub-committee was satisfied with these responses.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Interview schedules or topic guides for participants	3	15 October 2018
Notice of Substantial Amendment (non-CTIMP)	V4	04 October 2018
Other [Phase 2 Assent Form - Participants 12-15 years V4.0 04-10-18.docx]	4	04 October 2018
Participant consent form [Phase 2 Consent Form - Participants 16-19 years V4.0 04-19-18.docx]	4	04 October 2018
Participant consent form [Phase 2 Consent Form - Parents.Guardians V1.0 04-08-18.docx]	1	04 October 2018
Participant information sheet (PIS) [Phase 2 information sheet - Participants 16-19 years V 4.0 04-10-18.docx]	4	04 October 2018
Research protocol or project proposal	4	04 October 2018

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

17/LO/1694:	Please quote this number on all correspondence

Yours sincerely
PP:

C. Frost

Dr Ralph White
Chair

E-mail: nrescommittee.london-londonbridge@nhs.net

London - London Bridge Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 31 October 2018

Committee Members:

Name	Profession	Present	Notes
Ms Kate Melvin	Freelance Qualitative Researcher	Yes	
Dr Ralph White	Pharmacist	Yes	

Also in attendance:

Name	Position (or reason for attending)
Mr Connor Frost	REC Manager

Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro

Cardiff and Vale
University Health Board

Ysbyty Athrofaol Cymru
University Hospital of Wales

Heath Park,
Cardiff, CF14 4XW
Phone 029 2074 7747
Fax 029 2074 3838
Minicom 029 2074 3832

Parc Y Mynydd Bychan,
Caerdydd, CF14 4XW
Ffôn 029 2074 7747
Ffacs 029 20743838
Minicom 029 2074 3832

Tel: 029 20746986

CAV_Research.Development@wales.nhs.uk

From: Professor C Fegan
R&D Director
R&D Office, 2nd Floor TB2
University Hospital of Wales
Cardiff
CF14 4XW

13 November 2017

Professor J W Gregory
Consultant in Paediatric, Endocrinology
University Hospital of Wales
Heath Park
Cardiff
CF14 4XW

Dear Professor Gregory

Study title	Shared Decision-Making In Young People With Long-Term Conditions
Cardiff and Vale UHB reference	17/SEP/7069
IRAS reference	232192

The above project was forwarded to Cardiff and Vale University Health Board R&D Office by the Health and Care Research Wales Permissions Service. A Governance Review has now been completed.

I am pleased to inform you that based on the review of the documents submitted to the Health and Care Research Wales Permissions Service, the UHB has no objection to your proposal and that this study has been classed as pathway-to-portfolio.

You have informed us that Cardiff University is willing to act as Sponsor under the Research Governance Framework for Health and Social Care. Please accept this letter as confirmation of permission for the project to begin within this UHB.

I note that Health and Care Research Wales has determined that this study is ineligible for adoption onto the Clinical Research Portfolio and your Directorate R&D Lead has determined that it does not meet the criteria for Pathway-to-Portfolio. The

Bwrdd Iechyd Prifysgol Caerdydd a'r Fro yw enw gweithredol Bwrdd Iechyd Lleol Prifysgol Caerdydd a'r Fro
Cardiff and Vale University Health Board is the operational name of Cardiff and Vale University Local Health Board

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

Directorate R&D Lead has confirmed that he is satisfied that arrangements are in place for meeting any costs from outside of the R&D Activity Based Funding allocation

May I take this opportunity to wish you success with the project and remind you that as Chief / Principal Investigator you are required to:

* Inform the Health and Care Research Wales Permissions Service and the UHB R&D Office if any external or additional funding is awarded for this project in the future
* Ensure that all study amendments are submitted to the Health and Care Research Wales Permissions Service
* Ensure the Health and Care Research Wales Permissions Service is notified of the study's closure
* Ensure that the study is conducted in accordance with all relevant policies, procedures and legislation
* Provide information on the project to the UHB R&D Office as requested from time to time.

Yours sincerely,

Professor Christopher Fegan
R&D Director / Chair of the Cardiff and Vale Research Review Service (CaRRS)

CC

R&D Lead	Dr Philip Connor
Sponsor Contact	Cardiff University
Academic supervisor(s)	Dr Natalie Joseph-Williams
	Dr Fiona Wood
Student	Amber Jordan
Clinical Board Assistant Head of Finance	Becci Ingram
Finance	Anthony Williams

Participant Information Sheet

Shared Decision-Making in Young People with long-term Conditions
Researcher: Amber Jordan

I am a student in the school of Medicine at Cardiff University conducting this project as part of my PhD. I have previous research experience interviewing people with Type 2 diabetes about their attitudes and experiences with health services in South Wales. I would like to invite you to take part in a research study which looks at a way to prepare young people like yourself to become more involved during health consultations. The research would involve participation in a single one-on-one interview. The interview will take place at a time and location at your convenience and will not interfere with your education or work time.

Before you decide to take part, it is important for you to understand why the research is being done and what you would be asked to do if you took part. Please take time to read the following information carefully and discuss it with your friends, family, or GP if you wish. Please do not hesitate to contact me if there is anything that is not clear, or if you would like more information (contact details can be found at the bottom of the sheet). You do not have to decide straight away if you would like to take part in this research. Thank you for reading this.

What is this study about?

Shared decision-making is a key component of patient-centred care. It is a process in which patients and health professionals work together to make decisions and select treatment and care plans, based on professional expertise and patient preferences and values. Shared decision making is one way to improve care for adolescent patients with long-term conditions, and is actively supported by NHS bodies and patient organisations.

Previous research has found that although shared decision-making is stated as standard practice with young people, it often is not the reality. The project aims to look at reasons why young people with long-term conditions may or may not participate in shared decision-making during doctor's visits.

Why do you want me to take part?

We would like around 20 young people between the ages 12 and 19 years, who are living with a long-term condition, such as Type 1 diabetes, kidney disease, arthritis, or epilepsy to take part. We want to hear your views on what might motivate or prevent you from participating in shared decision-making.

What will happen if I do take part?

If you give your permission to take part, we would ask you to take part in one interview which will last about **one hour**. The interview will be audio recorded. It will take place at your home, the hospital or another place which is convenient for you. Interviews can also take place over the phone if meeting in person is not possible.

First, we will arrange a time that suits you to meet and I can explain the study in detail. I will then ask you to sign a form to show you are willing to be in the study. During the interview I will ask you to answer questions about consultations with the doctor. I will ask you to fill in in a timeline if you wish, which will provide me with information about your past experiences. Examples of the types of questions are: "*Tell me about your last visit with the doctor*", "*What decisions were made during that visit*?", *"How involved were you in making these decisions*?", "*What stopped you from being more involved in the decisions*?" "*What might make you want to be more involved in decisions about your healthcare in the future*?". You can skip any questions or activity you like or stop the interview at any time without giving a reason. Your parents can be there for this if you would like them to, although I

will ask them to try not to speak during the interview. The interview will not interfere with your care, and participating will not affect your care.

Are there any risks to me if I take part?
These questions are designed specifically for children and adolescents, and do not normally upset people. However, we will stop the interview straight away if you become tired or stressed in any way. You can also choose to end the interview or skip any questions as you like.

What are potential benefits?
By taking part in this study, you will be helping research which looks at improving healthcare for young people. The findings of this study will be used to develop health materials to prepare young people to participate in shared decision-making about their healthcare. You will be helping us identify issues which may stop young people from taking part. As a small token of thanks, you will be offered a £20 Amazon or Love2shop voucher to use at the shop of your choice (such as Boots, HMV, New Look, Pizza Express, WHSmith, etc.)

Who will know what I have said?
All information will be made anonymous, and confidentiality and security of all data will be maintained at all times. This means that recordings of the interviews will be kept on a password-controlled computer, and no real name or address will be saved with your interview. Direct quotations may be used, but they will be anonymised, which means no identifying information will be attached to the quote.

When the study is finished all information collected from interviews, such as recordings, transcripts and other study measures will be stored will be stored on a password protected computer in a locked drawer at Cardiff University, for a minimum of 15 years. It will then be destroyed.

What will happen once I have taken part in the study?
We will send you the transcripts of your interview and you can make changes if you think they do not represent your views.

We will send you a report which summarises the results and contains some individual quotes. These results may be submitted to an academic journal and presented at conferences and meetings, but this will be done anonymously; no one will know it was your results. This report will be written under the supervision of Dr Fiona Wood, Dr Natalie Joseph-Williams, and Prof Adrian Edwards at Cardiff University.

What if I change my mind about taking part in the study?
You have the right to withdraw from the study at any time with no consequences. This means that all your personal information will be disposed of and destroyed.

Who is organising the research?
Cardiff University is running and funding the study. Please note that the researchers are not being paid to do this research.

Who has reviewed the study?
In order to ensure that it is safe and appropriate for those taking part, all research is reviewed by a research panel. This study has been reviewed and approved by the NHS Research Ethics Committee, and the Research and Development office in the Cardiff and Vale area.

What if there is a problem?
If you have any questions or experience any difficulties, then please contact a member of the

research team. If you would like to make a complaint, please contact Dr Denitza Williams (contact details are below).

What do I do if I want to take part?

You can contact us by e-mail: **jordana3@cardiff.ac.uk** or telephone: **02920687643**. If you prefer for us to contact you, I have enclosed a 'study reply form' for you to share contact details and agree to be contacted if you would like to take part in the study. Please give details of how and when you would prefer to be contacted. You do not need to give both telephone number and e-mail address, just the one you prefer. We will then telephone you or send an e-mail to arrange the first meeting. We can only contact you if you return the signed 'study reply form' to us. You can use the self-addressed envelope provided. Alternatively, you can get in contact with us via the details below.

Further information and contact details

For further information about or if you would like to participate in the project please contact Ms Amber Jordan (email: jordana3@cardiff.ac.uk, phone: 02920687643) Cardiff University School of Medicine, Heath Park Campus, CF14 4WZ. We will be happy to answer any questions that you might have.

For any **complaints or concerns** please contact Dr Denitza Williams (email: stoilovado@cardiff.ac.uk, phone: 02920687809) Cardiff University School of Medicine, Heath Park Campus, CF14 4WZ.

Thank you for reading this information sheet

Participant Assent Form

I am Amber Jordan from Cardiff University. I am doing a study to see why young people with health conditions, such as diabetes, kidney disease, arthritis, or epilepsy, may or may not participate in healthcare discussions and decisions during doctors' visits. I am asking you to take part in this study because you have one of these health conditions.

For this research I will ask you some questions about your experiences when you visited the doctor. I will ask you to fill out a timeline with recent doctor's visits and describe them to me. I will also ask you to fill out a chart which shows how much you, your parents and the doctor were involved in the discussions and decisions. Finally, I will ask you some questions about why you might or might not participate more in healthcare discussions and decisions. You can have someone in the room with you during the interview if they like, but I will ask them not to speak unless there is a problem. I will audio record the interview, but what you said will be anonymous. I may use your quotes but will use a false name so nobody will know who said it.

We don't think that any big problems will happen to you as part of this study, but you might feel sad when asked about doctor's visits. You can skip any question you like without giving a reason.

By taking part you can help us to try to improve care for other young people with health conditions like you. As a thank you, we will give you a £20 Love2shop or Amazon voucher.

You should know that:
- **You do not have to be in this study if you do not want to. There will be no consequences if you say no.**
- **You may stop being in the study at any time, and you do not have to answer any question if you do not want.**
- **Your parent(s)/guardian(s) were asked if it is OK for you to be in this study. Even if they say it's OK, it is still your choice whether or not to take part.**
- **You can ask any questions you have, now or later. If you think of a question later, you or your parents can contact me at jordana3@cardiff.ac.uk**

Sign this form only if you:
- **have understood what you will be doing for this study,**
- **have had all your questions answered**
- **have talked to your parent(s)/legal guardian about this project, and**
- **agree to take part in this research**

_____   _____

Your signature   Date

Date

Participant Information Sheet

Shared Decision-Making in Young People with long-term Conditions
Researcher: Amber Jordan

I am a student in the school of Medicine at Cardiff University conducting this project as part of my PhD. My previous research experience involved asking people with Type 2 diabetes about their attitudes towards and experiences with health services in South Wales. I would like to invite your child to take part in a research study which looks at a way to prepare young people to become more involved during health consultations. The research would involve participation in a single one-on-one interview. The interview will take place at a time and place of your convenience and will not interfere with your child's education or work time.

Before you decide whether to give permission for your child to take part, it is important for you to understand why the research is being done and what your child would be asked to do if he/she took part. Please take time to read the following information carefully and discuss it with your friends, family, or GP if you wish. Please do not hesitate to contact me if there is anything that is not clear, or if you would like more information (contact details can be found at the bottom of the sheet). You do not have to decide straight away if you would like to provide consent for your child to take part in this research. Thank you for reading this.

What is this study about?
Shared decision-making is a key component of patient-centred care. It is a process in which patients and health professionals work together to make decisions and select treatment and care plans, based on professional expertise and patient preferences and values. Shared decision making is a way to improve care for young people with long-term conditions and is actively supported by NHS bodies and patient organisations.

Previous research has found that although shared decision-making is stated as standard practice with young people, it often is not the reality. The project aims to look at reasons why young people with long-term conditions may or may not participate in shared decision-making during doctor's visits.

Why do you want my child to take part?
We would like to interview 20 adolescents between the ages 12 and 19 years, who are living with a long-term condition, such as Type 1 diabetes, kidney disease, arthritis, or epilepsy. We want to hear your child's views on what might motivate or prevent your child from participating in shared decision-making.

What will happen if my child takes part?
If you give your permission for your child to take part, and they agree, we would ask your child to attend one interview which will last about **one hour**. The interview will be audio recorded. It will take place at your home, the hospital, or another place which is convenient for you and your child. Interviews can also take place over the phone if meeting in person is not possible. You will be compensated for any travel expenses. First, we will arrange a time that suits you and your child to meet and I can explain the study in detail. I will then ask you to sign a form to show you are willing for your child to be in the study. Your child will be asked to sign a form which says that they agree.

During the interview I will ask your child to answer questions about consultations with the doctor. I will ask him/her to fill in in a timeline, which will provide me with information about his/her past experiences. Examples of the types of questions are: "*Tell me about your last visit with the doctor*",

"*What decisions were made during that visit*?", *"How involved were you in making these decisions*?", "*What stopped you from being more involved in the decisions*?" "*What might make you want to be more involved in decisions about your healthcare in the future*?". He/she can skip any questions or activity he/she likes or stop the interview at any time without giving a reason. You can be present for this interview if you both wish, although I will ask that you do not speak during the interview unless you have any concerns. The interview will not interfere with your child's care, and participation will not affect their care.

Are there any risks to my child if he/she takes part?
These questions are designed specifically for children and adolescents, and do not normally upset people. However, we will stop the interview straight away if your child becomes tired or stressed in any way. Your child can also choose to end the interview or skip any questions as he/she likes.

What are potential benefits?
By taking part in this study your child will be helping research which looks at improving healthcare for young people. The findings of this study will be used to develop health materials to prepare young people to participate in shared decision-making about their healthcare. Your child will be helping us identify issues which may stop young people from taking part. As a small token of thanks, your child will be offered a £20 Amazon or Love2shop voucher to use at the shop of his/her choice (such as Boots, HMV, New Look, WHSmith, etc).

Who will know what my child has said?
All information will be made anonymous, and confidentiality and security of all data will be maintained at all times. This means that recordings of the interviews will be kept on a password-controlled computer, and no real name or address will be saved with your child's interview. Direct quotations may be used, but they will be anonymised, which means no identifying information will be attached to the quote.

When the study is finished all information collected from interviews, such as recordings, transcripts and other study measures will be stored on a password protected computer or in a locked drawer at Cardiff University, for a minimum of 15 years. It will then be destroyed.

What will happen once my child has taken part in the study?
Your child will be provided with transcripts of his/her interview and given the opportunity to make any changes if he/she thinks they are not representative of his/her views.

Your child will be sent a report which summarises the results and contains some individual quotes. These results may be submitted to a peer-reviewed journal and presented at conferences and meetings, but this will be done anonymously; no one will know it was your child's results. This report will be written under the supervision of Dr Fiona Wood, Dr Natalie Joseph-Williams, and Prof Adrian Edwards at Cardiff University.

What if I change my mind about my child taking part in the study?
You or your child have the right to withdraw from the study at any time with no consequences. This means all his/her personal information will be disposed of and destroyed.

Who is organising the research?
Cardiff University is running and funding the study. Please note that the researchers are not being paid to conduct this research.

Who has reviewed the study?
In order to ensure that it is safe and appropriate for those taking part, all research is reviewed by a

research panel. This study has been reviewed and approved by the NHS Research Ethics Committee, and the Research and Development office in the Cardiff and Vale area.

What if there is a problem?
If you have any questions or experience any difficulties, then please contact a member of the research team. If you would like to make a complaint, please contact Dr Denitza Williams (contact details are below).

What do I do if I want my child to take part?
You can contact us by e-mail: **jordana3@cardiff.ac.uk** or telephone: **02920687643**. If you prefer for us to contact you, enclosed is a study reply form for you to share contact details and agree to be contacted if you would like your child to take part in the study. Please give details of how and when you would prefer to be contacted. You do not need to give both telephone number and e-mail address, just the one you prefer. We will then telephone you or send an e-mail to arrange the first meeting. We can only contact you if you return the signed 'study reply form' to us. You can use the self-addressed envelope provided.

Further information and contact details

For further information about or if you would like to participate in the project please contact Ms Amber Jordan (email: jordana3@cardiff.ac.uk, phone: 02920687643) Cardiff University School of Medicine, Heath Park Campus, CF14 4WZ. We will be happy to answer any questions that you might have.

For any **complaints or concerns** please contact Dr Denitza Williams (email: stoilovado@cardiff.ac.uk, phone: 02920687809) Cardiff University School of Medicine, Heath Park Campus, CF14 4WZ.

Thank you for reading this information sheet

Participant Consent Form

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

Reference Number:
Participant Identification Number:
Title of Project: Phase 1: Shared Decision-Making in Young People with long-term Conditions V 2.0 19/10/17

Name of Researcher: Amber Jordan
Phone Number: 02920687643
E-mail address: Amber Jordan

_____

Participant to complete this section: **Please tick each box if you agree.**

1. I confirm that I have read and understand the information sheet and understand what is involved in my participation. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and with no consequences. If I decide to withdraw, all of my personal information will be disposed of. ☐

3. I agree to the interview consultation being audio recorded ☐

4. I agree to the use of anonymised quotes in publications ☐

5. I agree to take part in the above study. ☐

_____   _____
Signature of participant

                                                       Date
_____
Printed name of participant

_____   _____
Signature of person taking consent   Date

Participant Consent Form

Reference Number:
Participant Identification Number:
Title of Project: Phase 1: Shared Decision-Making in Young People with long-term Conditions V 2.0 19/10/17

Name of Researcher: Amber Jordan
Phone Number: 02920687643
E-mail address: Amber Jordan

_____

Parent to complete this section: **Please <u>tick</u> each box if you agree.**

1. I confirm that I have read and understand the information sheet and understand what is involved in my child's participation. My child and I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my child's participation is voluntary and that I or he/she is free to withdraw at any time without giving reason and with no consequences. If we decide to withdraw, all my child's personal information will be disposed of. ☐

3. I give consent for the interview consultation being recorded ☐

4. I give consent for the use of anonymised quotes in publications. ☐

5. I give consent for my child to take part in the above study ☐

_____   _____

Signature of parent/guardian

                                                                Date

_____

Printed name of parent/guardian

_____   _____

Signature of person taking consent   Date

Participant Information Sheet

Shared Decision-Making in Young People with long-term Conditions
Researcher: Amber Jordan

I am a student in the school of Medicine at Cardiff University doing this project as part of my PhD. My previous research experience involved asking people with Type 2 diabetes about their attitudes towards and experiences with health services in South Wales. I would like to invite you to take part in a research study which looks at a way to prepare young people to be more involved during health consultations. The research would involve participation in a single focus group interview. The focus group will take place at a time and location at your convenience and will not interfere with your education or work time.

Before you decide to take part, it is important for you to understand why the research is being done and what you would be asked to do if you took part. Please take time to read the following information carefully and discuss it with your friends, family, or GP if you wish. Please do not hesitate to contact me if there is anything that is not clear, or if you would like more information (contact details can be found at the bottom of the sheet). You do not have to decide straight away if you would like to take part in this research. Thank you for reading this.

What is this study about?
Shared decision-making is an important part of patient-centred care. It is way for patients and health professionals to work together to make decisions and choose treatment and care plans, based on professional expertise and patient preferences and values. Shared decision making is one way to improve care for adolescent patients with long-term conditions and is actively supported by NHS bodies and patient organisations.

Previous research has found that although shared decision-making is stated as standard practice with young people, it often is not the reality. This project aims to evaluate and improve materials designed to prepare/support adolescent involvement in shared decision-making.

Why do you want me to take part?
We would like to conduct two focus groups of approximately five teenagers each, with teenagers between the ages 12 and 19 years who are living with a long-term condition, such as Type 1 diabetes, kidney disease, arthritis, or epilepsy. We want to hear your feedback on the health materials we have designed.

What will happen if I do take part?
Participating will not affect your care. If you give your permission to take part, we would ask you to take part in one *focus group* which will last about **one hour**. You will first be sent a copy of the materials before the *focus group* so that you have had time to go through them. You can also make comments on the materials before the *focus group*.

We will arrange a time that is convenient for you and others to meet and I can explain the study in detail. I will then ask you to sign a form to show you are willing to be in the study. The focus group will be audio recorded. It will take place at the hospital or another public place which is convenient for the people involved. You will be compensated for any travel expenses. During the focus group I will ask everyone to go through each item of the materials we have developed and basically tell me what they think. I will then ask some questions about your overall views and ideas for improvement. You can

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skip any questions you like or leave the focus group at any time without giving a reason. Your parents can be there for this if you would like, although I will ask them to try not to speak during the focus group.

Are there any risks to me if I take part?
These questions are designed specifically for children and adolescents, and do not normally upset people. But we will stop the interview focus group straight away if anyone becomes tired or stressed in any way. You can also choose to leave the focus group or skip any questions as you like.

What are the possible benefits?
By taking part in this study, you will be helping research which looks at improving healthcare for young people. The findings of this study will be used to improve the materials we have developed and make them more acceptable for adolescents like you. As a small token of thanks, you will be offered a £20 Amazon or Love2shop voucher to use at the shop of your choice (such as Boots, HMV, New Look, WHSmith, etc).

Who will know what I have said?
All information will be made anonymous, and confidentiality and security of all data will be maintained at all times. This means that recordings of the focus groups will be kept on a password-controlled computer, and no real name or address will be saved with your recording. Direct quotations may be used, but they will be anonymised, which means no identifying information will be attached to the quote.

When the study is finished all information collected from the focus groups, such as recordings, transcripts and other study measures will be stored will be stored on a password protected computer in a locked drawer at Cardiff University, for a minimum of 15 years. It will then be destroyed.

What will happen once I have taken part in the study?
We will send you the transcripts of what you have said, and you can make changes if you think they do not represent your views. You can choose to withdraw from the study at any time with no consequences, which means all your personal information will be destroyed.

We will send you a report which summarises the results and contains some individual quotes. These results may be submitted to an academic journal and presented at conferences and meetings, but this will be done anonymously; no one will know it was your results. This report will be written under the supervision of Dr Fiona Wood, Dr Natalie Joseph-Williams, and Prof Adrian Edwards at Cardiff University.

Who is organising the research?
Cardiff University is running and funding the study. Please note that the researchers are not being paid to conduct this research.

Who has reviewed the study?
In order to ensure that it is safe and appropriate for those taking part, all research is reviewed by a research panel. This study has been reviewed and approved by the NHS Research Ethics Committee, and the Research and Development office in the Cardiff and Vale area.

What if there is a problem?
If you have any questions or experience any difficulties, then please contact a member of the research team. If you would like to make a complaint, please contact Dr Denitza Williams (contact details are below).

What do I do if I want to take part?

Enclosed is a 'study reply form' for you to share contact details and agree to be contacted if you would like to take part in the study. Please give details of how and when you would prefer to be contacted. You do not need to give both telephone number and e-mail address, just the one you prefer. We will then telephone you or send an e-mail to arrange the first meeting. We can only contact you if you return the signed 'study reply form' to us. You can use the self-addressed envelope provided. Alternatively, you can get in contact with us via the details below.

Thank you for reading this information sheet

Further information and contact details

For further information about the project please contact Ms Amber Jordan (email: jordana3@cardiff.ac.uk, phone: 02920687643) Cardiff University School of Medicine, Heath Park Campus, CF14 4WZ. We will be happy to answer any questions that you might have.

For any complaints or concerns please contact Dr Denitza Williams (email: stoilovado@cardiff.ac.uk, phone: 02920687809) Cardiff University School of Medicine, Heath Park Campus, CF14 4WZ.

Participant Assent Form

I am Amber Jordan from Cardiff University. I am doing a study to get the opinions of young people with health conditions such as diabetes, kidney disease, arthritis, or epilepsy, about health materials we have developed for them. The health materials were developed to prepare and support the involvement of young people in discussions and decisions about their health. I am asking you to take part in this study because you are between 12 and 19 years old and have one of the health conditions I mentioned.

For this research I will ask you to go through the materials we have developed for young people like you in a small group of about five young people. When we go through them, I will ask everyone to think aloud about their thoughts on each part. Finally, I will ask everyone questions about their overall views and ideas as to whether anything can be made better. You can have a parent in the room with you during the interview if you like, but I will ask them not to speak unless there is a problem. I will audio record the focus group, with permission, but what you say will be anonymous outside of the group. I may use your quotes, but these will be anonymised and every attempt will be made to ensure that no-one can be identified by any other reference.
We don't think that any big problems will happen to you as part of this study, but you might feel sad when you think about your condition. You can skip any question without giving a reason or leave the group at any time.

By taking part you can help us to try to improve care for other young people with health conditions like you. As a thank you, we will give you a £20 Amazon or Love2shop voucher to use at a shop of your choice (such as Boots, New Look, WHSmith, etc.).

You should know that:
- **You do not have to be in this study if you do not want to. There will be no consequences if you say no.**
- **You may stop being in the study at any time, and you do not have to answer any question if you do not want.**
- **Your parent(s)/guardian(s) were asked if it is OK for you to be in this study. Even if they say it's OK, it is still your choice whether or not to take part.**
- **You can ask any questions you have, now or later. If you think of a question later, you or your parents can contact me at jordana3@cardiff.ac.uk**

Sign this form only if you:
- **have understood what you will be doing for this study,**
- **have had all your questions answered**
- **have talked to your parent(s)/legal guardian about this project, and**
- **agree to take part in this research**

_____   _____

Your signature   Date

_____

Printed name

_____   _____

Signature of person taking consent   Date

Participant Information Sheet

Shared Decision-Making in Young People with long-term Conditions
Researcher: Amber Jordan

I am a student in the school of Medicine at Cardiff University conducting this project as part of my PhD. My previous research experience involved asking people with Type 2 diabetes about their attitudes towards and experiences with health services in South Wales. I would like to invite your child to take part in a research study which looks at a way to prepare young people to become more involved during health consultations. The research would involve participation in a single one-on-one focus group. The focus group will take place at a time and place of your convenience and will not interfere with your child's education or work time.

Before you decide whether to give permission for your child to take part, it is important for you to understand why the research is being done and what your child would be asked to do if he/she took part. Please take time to read the following information carefully and discuss it with your friends, family, or GP if you wish. Please do not hesitate to contact me if there is anything that is not clear, or if you would like more information (contact details can be found at the bottom of the sheet). You do not have to decide straight away if you would like to provide consent for your child to take part in this research. Thank you for reading this.

What is this study about?
Shared decision-making is a key component of patient-centred care. It is a process in which patients and health professionals work together to make decisions and select treatment and care plans, based on professional expertise and patient preferences and values. Shared decision making is a way to improve care for adolescents with long-term conditions and is actively supported by NHS bodies and patient organisations.

Previous research has found that although shared decision-making is stated as standard practice with young people, it often is not the reality. This project aims to evaluate and improve materials we have developed to prepare/support adolescent involvement in shared decision-making.

Why do you want my child to take part?
We would like to conduct two focus groups of approximately five teenagers between the ages 12 and 19 years, who are living with a long-term condition, such as Type 1 diabetes, kidney disease, arthritis, or epilepsy. We want to hear your child's feedback on the health materials we have designed.

What will happen if my child takes part?
Participation will not affect your child's care. If you give your permission for your child to take part, and they agree, we would ask your child to attend one focus group which will last about **one hour**. Your child will first be sent a copy of the materials before the focus group so that they have had time to go through them.

We will arrange a time that suits you and your child and others to meet and I can explain the study in detail. I will then ask you to sign a form to show you are willing for your child to be in the study. Your child will be asked to sign a form which says that they agree. The focus group will be audio recorded. It will take place at your home, the hospital or another place which is convenient for the people involved. You will be compensated for any travel expenses. During the focus group I will ask everyone to go through each item of the materials and tell me what they think. I will then ask some questions about your overall views and ideas for improvement. Some examples of the types of questions I will ask are: "*What are your overall impressions of the materials*", "*What do you think might be difficult for*

you to understand?", "*What improvements would you suggest?*" "*Is there anything you think we should add/remove?*". He/she can skip any questions he/she likes or leave the focus group at any time without giving a reason. You can be present for this focus group if you both wish, although I will ask that you do not speak during the focus group unless you have any concerns. The focus group will not interfere with your child's care, and participation will not affect their care.

Are there any risks to my child if he/she takes part?
These questions are designed specifically for children and adolescents, and do not normally upset people. However, we will stop the focus group straight away if anyone becomes tired or stressed in any way. Your child can also choose to leave the focus group or skip any questions as he/she likes.

What are potential benefits?
By taking part in this study your child will be helping research which looks at improving healthcare for young people. The findings of this study will be used to improve the materials and make them more acceptable for adolescents like your child. As a small token of thanks, your child will be offered a £20 Love2shop or Amazon voucher.

Who will know what my child has said?
All information will be made anonymous, and confidentiality and security of all data will be maintained at all times. This means that recordings of the focus groups will be kept on a password-controlled computer, and no real name or address will be saved with your child's focus group. Direct quotations may be used, but they will be anonymised, which means no identifying information will be attached to the quote.

When the study is finished all information collected from focus groups, such as recordings, transcripts and other study measures will be stored on a password protected computer or in a locked drawer at Cardiff University, for a minimum of 15 years. It will then be destroyed.

What will happen once my child has taken part in the study?
Your child will be provided with transcripts of his/her focus group and given the opportunity to make any changes if he/she thinks they are not representative of his/her views.

Your child will be sent a report which summarises the results and contains some individual quotes. These results may be submitted to a peer-reviewed journal and presented at conferences and meetings, but this will be done anonymously; no one will know it was your child's results. This report will be written under the supervision of Dr Fiona Wood, Dr Natalie Joseph-Williams, and Prof Adrian Edwards.

What if I change my mind about my child taking part in the study?
You or your child have the right to withdraw from the study at any time with no consequences. This means all his/her personal information will be disposed of and destroyed.

Who is organising the research?
Cardiff University is running and funding the study. Please note that the researchers are not being paid to conduct this research.

Who has reviewed the study?
In order to ensure that it is safe and appropriate for those taking part, all research is reviewed by a research panel. This study has been reviewed and approved by the NHS Research Ethics Committee, and the Research and Development office in the Cardiff and Vale area.

What if there is a problem?
If you have any questions or experience any difficulties, then please contact a member of the

research team. If you would like to make a complaint, please contact Dr Denitza Williams (contact details are below).

What do I do if I want my child to take part?

Enclosed is a 'study reply form' for you to share contact details and agree to be contacted if you would like your child to take part in the study. Please give details of how and when you would prefer to be contacted. You do not need to give both telephone number and e-mail address, just the one you prefer. We will then telephone you or send an e-mail to arrange the first meeting. We can only contact you if you return the signed 'study reply form' to us. You can use the self-addressed envelope provided. Alternatively, you can get in contact with us via the details below.

Further information and contact details

For further information about the project please contact Ms Amber Jordan (email: jordana3@cardiff.ac.uk, phone: 02920687643) Cardiff University School of Medicine, Heath Park Campus, CF14 4WZ. We will be happy to answer any questions that you might have.

For any complaints or concerns please contact Dr Denitza Williams (email: stoilovado@cardiff.ac.uk, phone: 02920687809) Cardiff University School of Medicine, Heath Park Campus, CF14 4WZ.

Thank you for reading this information sheet

Participant Information Sheet

Shared Decision-Making in Young People with long-term Conditions
Researcher: Amber Jordan

I am a student in the school of Medicine at Cardiff University doing this project as part of my PhD. I would like to invite you to take part in a research study which is looks at a way to prepare young people to be more active during health consultations. The research would involve participation in a single one-on-one interview. The interview will take place at a time and location at your convenience.

Before you decide to take part, it is important for you to understand why the research is being done and what you would be asked to do if you took part. Please take time to read the following information carefully and discuss it with others if you wish. Please do not hesitate to contact me if there is anything that is not clear, or if you would like more information (contact details can be found at the bottom of the sheet). You do not have to decide straight away if you would like to take part in this research. Thank you for reading this.

What is this study about?
Sometimes, young adolescents living with long-term conditions will have decisions to make about their healthcare. They will have treatment options available to them and each option will have pros and cons. We believe that the best decisions are made when patients and healthcare professionals work together to make a decision that's right for the patient – we call this 'shared decision making'. However, some patients, young patients in particular are surprised when they are presented with treatment options. We would like to prepare adolescents living with long-term conditions for shared decision making by sending them information ahead of their healthcare appointments.

We have developed materials to help prepare adolescents living with long-term condition to become more involved in making healthcare decisions together with healthcare professionals. We want various hospital teams to send this information to patients ahead of their appointments. We want to involve patients and healthcare professionals in the development of this information, and this is why we are conducting this study. We want your opinions on the content and design of the information so that we can improve it. We also want to know how we can best use it in clinical teams.

Why do you want me to take part?
We are asking healthcare practitioners that work with adolescents living with long-term conditions to take part and provide feedback on the materials we have developed, including suggestions for improvement.

Do I have to take part?
No. Participation in the study is completely voluntary

What will happen if I do take part?
If you agree to take part in the study, we will ask you to take part in an interview with our researcher. You will be sent a copy of the materials before the interview so that you have had time to read it. You can also make comments on the materials before the interview. The interview will take place at a time and location that is convenient to you and should take no longer than one hour.

During the interview, you will be asked what you thought about the materials. We will ask you what you thought about the design (e.g., colours, layout), the content (e.g., how easy it was to understand), and also whether you think it will help patients to become more involved in healthcare decisions. During the interview I will ask you to go through each item of the materials and tell me what you think. I will then ask some questions about your overall views and ideas for improvement. We are also interested to know how you think that it can be used in clinical settings. Some examples of the types

of questions I will ask are: "*What are your overall impressions of the materials*", "*What do you think might be difficult for your patients to understand*?", "*What improvements would you suggest*?" "*Is there anything you think we should add/remove*?". You can skip any questions you like or stop the interview at any time without giving a reason. The interview will be recorded so that the researcher has a record of your feedback.

Are there any risks to me if I take part?
There are no risks or disadvantages in taking part in the project. The study involves exploring your views of materials that we have developed. You do not have to talk about any issues that you do not want to discuss. If you find the interview uncomfortable (which we do not expect), you can withdraw at any time.

What are the possible benefits of taking part?
By sharing your feedback on materials, you will be helping us to improve information that we will be giving to patients. It will also help inform the way in which we distribute the information to patients.

What happens to my personal details?
A team at Cardiff University are carrying out this study. Data will be stored on secure, password-protected University computers and will only be accessed by the researchers. The data will be anonymised so that it is not linked to individual participants, and all audio recordings will be deleted within one year of the end of your participation in this study.

When the study is finished all information collected from interviews, such as recordings, transcripts and other study measures will be stored will be stored on a password protected computer in a locked drawer at Cardiff University, for a minimum of 15 years. It will then be destroyed.

What will happen once I have taken part in the study?
The results of the interviews will be used to improve the information that we have developed, and the way in which the information is used. The results might also be published in medical journals and presented at conferences. All personal details about you will be removed from any reports and presentations about the research. Any quotes from the interviews used in publications or presentations will be anonymised. This report will be written under the supervision of Dr Fiona Wood, Dr Natalie Joseph-Williams, and Prof Adrian Edwards. A copy of the final materials created after the interview feedback can be sent to you after the study.

What happens if I want to withdraw?
You have the right to withdraw from the study at any time with no consequences. All personal information will then be disposed of and destroyed.

Who is organising the research?
Cardiff University is running and funding the study. Please note that the researchers are not being paid to conduct this research.

Who has reviewed the study?
In order to ensure that it is safe and appropriate for those taking part, all research is reviewed by a research panel. This study has been reviewed and approved by the NHS Research Ethics Committee, and the Research and Development office in the Cardiff and Vale area.

What if there is a problem?

If you have any questions or experience any difficulties, then please contact a member of the research team. If you would like to make a complaint, please contact Dr Denitza Williams (contact details are below).

Further information and contact details

For further information about the project please contact Ms Amber Jordan (email: jordana3@cardiff.ac.uk, phone: 02920687643) Cardiff University School of Medicine, Heath Park Campus, CF14 4WZ. We will be happy to answer any questions that you might have.

For any complaints or concerns please contact Dr Denitza Williams (email: stoilovado@cardiff.ac.uk, phone: 02920687809) Cardiff University School of Medicine, Heath Park Campus, CF14 4WZ.

Thank you for reading this information sheet

Participant Consent Form

Reference Number:
Participant Identification Number:
Title of Project: Phase 2: Shared Decision-Making in Young People with long-term
Conditions

Name of Researcher: Amber Jordan

_____

Participant/parent to complete this section: **Please _initial_ each box.**

6. I confirm that I have read and understand the information sheet and
    understand what is involved in my participation. I have had the
    opportunity to consider the information, ask questions and have had
    these answered satisfactorily.

7. I understand that my participation is voluntary and that I am free to
    withdraw at any time without giving any reason.

8. I agree to the focus group being audio recorded

9.   I agree to the use of anonymised quotes in publications

10. I agree to take part in the above study.

_____   _____
Signature of participant
                                        Date

_____
Printed name of participant

_____   _____
Signature of person taking consent   Date

Participant Consent Form

Reference Number:
Participant Identification Number:
Title of Project: Phase 2: Shared Decision-Making in Young People with long-term Conditions
.

Name of Researcher: Amber Jordan
_____

Participant/parent to complete this section: **Please <u>initial</u> each box.**

1. I confirm that I have read and understand the information sheet and understand what is involved in my child's participation. My child and I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.   ☐

2. I understand that my child's participation is voluntary and that I or he/she is free to withdraw at any time without giving any reason.   ☐

3. I give consent for the focus group to be recorded   ☐

4. I give consent for the use of anonymised quotes in publications.   ☐

5. I give consent for child to take part in the above study   ☐

_____   _____
Signature of parent/guardian
                                                                        Date

_____
Printed name of parent/guardian

_____   _____
Signature of person taking consent   Date

Participant Consent Form

Reference Number:
Participant Identification Number:
Title of Project: Phase 2: Shared Decision-Making in Young People with long-term Conditions

Name of Researcher: Amber Jordan
_____

Participant/parent to complete this section: **Please <u>initial</u> each box.**

1. I confirm that I have read and understand the information sheet and understand what is involved in my participation. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw without giving any reason.

3. I agree to the interview consultation being audio recorded

4. I agree to the use of anonymised quotes in publications

5. I agree to take part in the above study.

_____ _____
Signature of participant

                                                                    Date

_____
Printed name of participant

_____ _____
Signature of person taking consent   Date

GIG CYMRU NHS WALES | Bwrdd Iechyd Prifysgol Caerdydd a'r Fro | Cardiff and Vale University Health Board

Dear

Our team is committed to making sure that our patients are involved in decisions about their healthcare treatment. We want to know what is important to you and believe that there are many benefits of making decisions together with our patients.

A team of researchers at Cardiff University are looking to develop materials to prepare and support the involvement of young people with long-term conditions, such as type 1 diabetes, in decisions about their healthcare. They want to know what might motivate or prevent your participation in making healthcare decisions.

I am contacting you to see if you might be interested in taking part in this study, I have enclosed an information sheet telling you about the study just in case you are interested in taking part. If you are interested, you can return the study reply from using the self-addressed envelope, which gives permission for the researcher to contact you. Nobody will receive your details without permission. Agreeing to be contacted does not mean you have to participate in the study.

It is up to you if you want to take part. You do not have to give a reason if you do not want to take part and your healthcare will not be affected. Please feel free to contact me if you have any questions. Alternatively, you can get in touch with a member of the research team on 029 206 87643 or jordana3@cardiff.ac.uk. You will also be able to ask questions about the study on the day of your appointment if you would like any further information.

Thank you for taking the time to read this letter.

Yours sincerely

3.16 Example invitation letter parents/guardians

![GIG CYMRU NHS WALES — Bwrdd Iechyd Prifysgol Caerdydd a'r Fro — Cardiff and Vale University Health Board]

Dear

Our team is committed to making sure that our patients are involved in decisions about their healthcare treatment. We want to know what is important to your child and believe that there are many benefits of making decisions together with our patients.

A team of researchers at Cardiff University are looking to develop materials to prepare and support the involvement of young people with long-term conditions, such as type 1 diabetes, in decisions about their healthcare. They want to know what might motivate or prevent their participation in making healthcare decisions.

I am contacting you to see if your child might be interested in taking part in this study, I have enclosed an information sheet telling you about the study just in case you are interested. If you are interested, you can return the study reply from using the self-addressed envelope, which gives permission for the researcher to contact you. Nobody will receive your details without permission. Agreeing to be contacted does not mean your child has to participate in the study.

It is up to you and your child whether to take part. You do not have to give a reason if you do not want them to take part and their healthcare will not be affected. Please feel free to contact me if you have any questions. Alternatively, you can get in touch with a member of the research team on 029 206 87643 or jordana3@cardiff.ac.uk. You and your child will also be able to ask questions about the study on the day of your child's appointment if you would like any further information.

Thank you for taking the time to read this letter.

Yours sincerely

Study Reply Form

Shared Decision-Making in Young People with long-term Conditions

Amber Jordan

Division of Population Medicine, Cardiff University, 5th Floor Neuadd Meirionnydd,

Heath Park, Cardiff, CF14 4YS. Email: jordana3@cardiff.ac.uk Tel: 029 206 87809

Please complete this form if you would like to be contacted for your child to take part in the above study

I confirm that I am happy to be contacted in order for my son/daughter to take part in the above study

Participant Name (Block Capitals): _____

Signature: _____ Date: _____

I would prefer to be contacted by (please tick one):

☐ Telephone   ☐ E-mail   ☐ Either

Please provide your preferred contact details below so that we can contact you to arrange an interview

Telephone number(s) _____ Preferred time of contact __

OR

E-mail _____

Please return this form in the pre-paid envelope provided

Study Reply Form

Shared Decision-Making in Young People with long-term Conditions

Amber Jordan

Division of Population Medicine, Cardiff University, 5th Floor Neuadd Meirionnydd,

Heath Park, Cardiff, CF14 4YS. Email: jordana3@cardiff.ac.uk Tel: 029 206 87809

Please complete this form if you would like to be contacted to take part in the above study

I confirm that I am happy to be contacted to take part in the above study

Participant Name (Block Capitals):_____

Signature:_____Date:_____

I would prefer to be contacted by (please tick one):

☐ Telephone   ☐ E-mail   ☐ Either

Please provide your preferred contact details below so that we can contact you to arrange an interview

Telephone number(s) _____ Preferred time(s) of contact_____

OR

E-mail _____

Please return this form in the pre-paid envelope provided

Thank you for taking part in our study

Your participation will help us to develop materials which to improve healthcare for young people with conditions like yours.

How to contact us: If you have any questions relating to the research project, you can contact me:

Amber Jordan, +44 (0)2920687643
Jordana3@cardiff.ac.uk

If you want to raise a concern about the research, you can contact:

Dr Denitza Williams +44 (0) 02920687809
stoilovado@cardiff.ac.uk

If you would like support or have questions concerning your condition or healthcare, including medication and treatment, please contact your clinical team

If you would like emotional support, you can contact:

Appendix 4. Chapter 4 - Map of coding resulting from thematic analysis

Why should I read this booklet?

Around **30% of young people** are affected by one or more long-term health conditions like eczema, asthma, epilepsy, diabetes, arthritis and many more.

In most of these cases, there will be choices of how YOU can manage YOUR condition.

When different healthcare choices are available, your doctors and nurses want you to be involved in these decisions, which affect YOU and YOUR life, and will support your involvement.

Doctors and nurses are experts on health conditions and treatments, but YOU are the expert on YOU and YOUR life.

Teenagers with long-term conditions say that the benefits of being involved in decisions with doctors include: feeling more positive and confident, less worried, and more satisfied with the decision.

Being involved in discussions and decisions with your doctor or nurse means you can find the best treatment/ healthcare plan that really suits YOU and YOUR lifestyle.

"SPEAK UP, BE INVOLVED, TALK ABOUT IT. IF YOU'RE INVOLVED YOU'LL KNOW WHAT'S GOING ON"

You can use this booklet as a guide to help you be more involved in healthcare/treatment decisions. You can have a read through before your appointment, and go through it with your doctor or nurse.

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How can I become more involved?

You can start by taking this quiz...

1 Do you have a healthcare/treatment choice?

YES I DO

I'M NOT SURE

Go to question 2

Start by asking your doctor or nurse "Do I have a choice?"

2 Do you understand your available healthcare/treatment options?

YES, I UNDERSTAND

NO, I'M UNSURE

Go to question 3

You can ask your doctor or nurse "What are my options?"

3 Do you understand the benefits and risks of your healthcare/treatment options?

YES, IT'S QUITE CLEAR TO ME

I'M NOT SURE

Great, you can fill in the chart on page 5 to help you keep track

You can ask your doctor or nurse: "What are the benefits and risks of each option for me?"

You may have some other specific questions.
Feel free to use the page at the back to write them down.

What is most important to me?

Here are some important self-management issues teenagers with longterm health conditions have mentioned. You can tick the one(s) which are most important to you and/or add some of your own.

○ Best fits in with my schedule

○ Fewest side-effects

○ Least likely to make me drowsy

○ Least likely to make me gain or lose weight

○ Easiest to remember

○ Lets me get on with my normal life as much as possible

○ Least obvious to others

○ Doesn't overly interfere with my sports/hobbies

○ Least effect on my mental health

○ Best at controlling symptoms

○ _____

○ _____

○ _____

○ _____

○ _____

○ _____

○ _____

○ _____

○ _____

○ _____

4

Weighing the options up...

Now that you know about your options, you can talk to your doctor or nurse to find which one might be best for you. You can do this by looking at the benefits and risks for each of the options, and comparing these to what is most important to YOU. You can fill this out to help you, and ask your doctor or nurse for support.

Option	Benefits +	Risks −

Now you have considered your available options and what's most important to you, which option(s) do you think might be best for you?

"YOU NEED TO ASSESS YOUR LIFESTYLE AND SEE WHAT FITS IN WITH THAT"

....

How confident do you feel that you can go through with this option?

1 2 3 4 5 6 7 8 9 10

Not confident at all   Very confident

5

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Here are some questions and concerns that teenagers brought up...

What if I make the wrong decision?

Your input is important, but you don't have to make any decisions on your own. Doctors and nurses won't suggest options that are "wrong" for you. Many decisions can be changed at your next appointment.

What if my mum/dad wants to be involved in the decision as well?

The last page of this booklet has been designed for you to give to your parents to read, if you like. You can ask to speak to the doctor or nurse alone for whatever reason, if you want.

Sometimes I can't be bothered discussing things with the doctor or nurse

You don't always HAVE to be involved, but it can be helpful. Remember, doctors and nurses WANT to help you to have the best healthcare or treatment for you. Being involved can achieve that.

"WHAT YOU THINK MATTERS, AND DOCTORS ARE THERE TO SUPPORT YOU"

6

I don't always like to think or talk about my condition

Thinking or talking about a health condition that affects you can be stressful. You can be in control of how little or how much you want to know. This may change over time and that's okay.

I'm worried I'm going to ask or say something stupid

It's quite common to think this, in fact almost everyone does at some point. Think about it this way; if you don't ask, you won't know, and your doctors and nurses WANT you to be fully informed about your condition and your healthcare or treatment. Also, nothing you say is stupid.

"IF YOU TELL DOCTORS WHAT YOU THINK THEN THEY'LL TAKE THAT INTO CONSIDERATION, THEN IT BEST SUITS THE DECISIONS BECAUSE THEY ARE SUITED TO YOU"

You may have more questions or concerns, feel free to bring them up with a member of your healthcare team. There is space for you to write these at the back of this booklet.

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Teenagers with long-term conditions speak about their experiences being involved in decisions with healthcare profressionals...

"HAVING A SAY HELPS YOU LEARN TO LIVE WITH YOUR CONDITION IN A WAY THAT YOU CAN, IN THE BEST WAY POSSIBLE"

"I was diagnosed with Type 1 diabetes when I was a baby. I was injecting insulin up to 5 times a day. I didn't like having to leave class to inject, and felt awkward doing it in front of my friends, so I sometimes missed injections. I brought this up with his doctor, and we discussed the option of trying an insulin pump. I wasn't sure at first because I met a guy who had one, and he didn't get on with it. But we decided I would give it a go, and it turned out to be a really good option for me. I was glad to have a say in that decision"

Rhys, aged 15

"I was diagnosed with epilepsy 6 years ago. Last year, I had to change medications because I was having more seizures than before, I think it might have been due to the stress of GCSEs. I didn't think changing medications at this time was suitable personally, but I wasn't really involved in that decision because I was feeling really tired during the appointment, and preoccupied with my exams. It didn't really turn out well, and at the next appointment I spoke with my consultant and we decided to change again. I'm the one taking the tablets, so I think it's important that I'm involved in deciding if I actually wanna go on a certain medication or not. It was much better that I was involved in the decision of coming off the one and starting a new one, and I was happy about that.

Aamaal, aged 17

"I've had arthritis for 2 years. At first, I felt quite nervous talking with the doctors and nurses, and would rather my parents do it for me. But then I realised it's better for me to participate because it's about me. It could affect my school, or other parts of my life, like playing guitar, and my parents didn't always get it right. Now I try to ask as many questions as I can, try to get myself more involved, and speak to the doctor myself instead of getting somebody else to speak for me. When I ask questions, the doctors answer them, they don't mind me speaking, they like that I'm involved, and I feel like I have a say"

Carys, aged 16

"DON'T BE AFRAID TO SPEAK OUT/ASK QUESTIONS"

Parents' section

Feel free to give this section to your mum/dad to have a read.

The purpose of this booklet is to encourage and support your daughter/son to be more involved in discussions and decisions about their healthcare or treatment.

NHS bodies and patient organisations actively support the involvement of patients in these decisions, and believe it is beneficial to them and their healthcare needs.

There are many benefits of your daughter/son's involvement in the discussions and decisions about their healthcare such as; increased knowledge, confidence, and selecting care or treatment that is best suited to them.

You can help by supporting you daughter/son's involvement, encouraging them to ask and answer questions, voice preferences and speak directly to the doctors and nurses.

They may like to speak to the doctor about something on their own, which is perfectly fine, and is good practice for when they're older.

"NOBODY ELSE KNOWS WHAT IT'S LIKE NOW APART FROM YOU, SO HOW'S A DOCTOR GOING TO MAKE THAT DECISION FOR YOU?"

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Your questions...

Appendix 6. Chapter 6 - Development of the analytical framework

Capability
- knowledge and awareness
  - condition/option knowledge
  - how to be involved
- Confidence in skills, ability and expertise
  - decision process ability
  - memory
  - self-efficacy

Opportunity
- Reassurance and support
  - social support/ encouragement
  - reassurance
  - Social influence
- Shared experience and social norms
  - social norms
  - not alone
  - relatable

Motivation
- right, control and ownership
  - entitlement
  - empowerment
  - taking responsability
- Perceptions attitudes and expectations
  - reduced fear and stress
  - feeling positive
  - outcome expectation
- Relevant and bespoke
  - Individual/ Personalised
 - Relevant
  - Inclusive

Appendix 7. Chapter 6 -Matrices of themes and participants with summaries and exemplary quotations

Session	Capability		Opportunity		Motivation		
	Knowledge and awareness of how to be involved and where to begin	Having the confidence in skills, expertise, and ability to be involved.	Perceived Reassurance and support	Shared experience and social norms	It is their right; they have control and ownership over their involvement and treatment plans	Perceptions, attitudes, and outcome expectations	Personally relevant and bespoke
Focus Group 1		The booklet can improve confidence around asking questions and decision-making Leah: "*it's saying uh have confidence [mmhm yeah] to talk to the doctors or nurse about how you feel, about your condition, and likes makes you feel better about it* "	The booklet informs users that HCPs want them to be involved and that assistance is available Robert: "*Straight off it reassures you that there are places to go if you need to speak to people*"	The booklet can make users feel less alone Robert: "*I think reading me stories some people, it will make them feel less uh* Leah: " *lonely –*" Robert: "*yeah lonely, in some cases also uh just you know like I said you hang out with your friends whatever*"	The booklet gives the message that adolescents have the right to be involved and their input is important Robert: "*my opinion important, and it's maybe not just what the doctor says, or just what my parents says all the time*	The booklet highlights the positives around involvement Leah: "*so I think that's really positive um I like that it's got uh lots of different quotes uh I like that it's, it's really trying to help people kind of um understand really that it's ok to kind of, to kind of get more involved in their uh Healthcare decisions* "	The booklet draws attention to the fact that every person will have a different set of priorities and desires from their care. Robert: "*depends on the person doesn't it. Different things work for different people*"
Focus Group 2	The booklet provides guidance and support to become more involved. Jade: "*Yeah, well it gives you good advice about what to do to get more involved and it encourages you, encouraging.*	The booklet helps you remember what you want to ask/say and improves confidence around being involved. Liz: "*like all the stuff in there um uh it has a questions page in the back where you can write all your questions down if you like, you don't wanna say it, you can just show them what you want to ask, so yeah like different ways you can be involved*".	The booklet encourages users to engage with HCPs Jade:" *I think I have a choice, and I understand my options, well most of them. But like it says here, you can ask, ask your doctor*"	Users can relate to stories of other adolescents and feel less alone Jade: "*Yeah easy, I like that other teenagers said these, and I agree with a lot of them, it's easy to choose*" Evan:" *Yeah, easy*"	The booklet can empower adolescents to choose their involvement Evan: "*yeah, I like it because it's like you don't have to because sometimes you really just don't don't want to. But you, it's good for you because then you know what's going to happening, you're always like more in control*"	The booklet demonstrates the benefits of being involved and can reduce negative emotions Liz: "*the saying like I've actually found it really useful to talk and learning to live and speaking out about my condition, because then they help me, and I can learn and manage in the best way possible for me*"	The booklet enables users to select preferences and option risk/benefits, making option section individualised. Jade: "*You can um manage your condition with like um like pumps or insulin, you can choose which one you want to use, which one's better for you and you can have a say with that. This (Pages 4 and 5) like helps to see which is best for you*"
Focus Group 3	The booklet provides guidance on how to be involved and obtain more information when options are unknown. Ashley: "*like gives the questions to ask, and if they don't know if they do have a choice who they can go to about their healthcare and stuff*"	The booklet can improve confidence around asking questions and making a "good" decision and can help users remember what to ask/say Carys: "*um I feel like the way that the options thing to fill it, with the list of what is most important to me, I feel like people, people don't often do that. It's hard to mentally weigh up the pros and cons. Once it's written down, I feel like uh it would help people a lot more to make a um a good*	The booklet reassures users that involvement is encourage, and may facilitate parental support Ashley: "*Yes yes, this bit is good. Like I definitely would give this to my mum to get her to like back off (laughs) not sure it would work, but it's good like how it says how they should support, like be supporting us, but it's good to see the doctor alone to.*" Carys: "*yeah, I'd give it to them, yeah* "	Relatable stories and users feel less alone Dai: "*I didn't know that about the like 30%, that's a lot more than, like more than I woulda said because I feel like out of my friends, I'm the only one. But I suppose people have other things like it says ec eczema, is that how you say it? not so serious as like my case maybe, but it's still something you gotta live with.*"	Users feel empowered by the booklet feel that it is their right to be involved. Ashley: "*Um, yeah like when I first saw it, like after everything "it's my body, I can have a say" is quite an empowering title.*	The booklet can enable users to view involvement positively and recognise the benefits Ashley: "*you can see how it's important first um like for the young adults to have more involvement in decisions like for the future and stuff like that.*"	The booklet helps users to recognising that adolescents with LTCs will have a different set of priorities and desires from their care. Dai: "*like weigh out the good and bad parts of each, like according to your like your um life*"

	decision, the right decision for them".						
Focus Group 4	The booklet provides guidance on how to be involved and obtain more information. Lowri: "*And it helps you to know what to say, or like what you should know, like the risks benefits thingie. I've like never asked that question, and I think sometimes they don't say all the risks*"	The booklet can improve confidence around decision-making and asking questions and act as a memory aid. Zoe: *Yeah, I think the "what if I make the wrong decision" one' good because I think personally if like they told me to make an important decision I'd be worrying if I was making the right decision* Eleri: "*Yeah, that's quite good because everyone always worries about that. Even when choosing A-levels and things*"	The booklet stresses that HCPs want adolescents to be involved Lowri: "*yeah yeah, and um saying how that they, like doctors and nurses, want you to be involved. It's like a reminder, they don't just want to tell you what to do, like they prefer your input because it's important, and it's about you*"	Relatable stories and users feel less alone Lowri: *like the first one kind of makes you feel not alone, like lots of people have like different things* Zoe: *Yeah yeah, and um, it's about, it's not just you……so sort of like you're not alone*	The booklet is seen as empowering and tells users their say is important Dylan: *It's like pushing, empowering you to actually be like-* Seren: *Get involved* Dylan: *get involved with your like illness rather than just leaving to your mum and dad to explain what's wrong with you, because then you can explain what it feels like person- to you personally*	The booklet gives positive messages around the benefits of taking part in decision making. Dylan: "*you're the one in charge, you don't have to, you can let someone else do it but um you'd, they can be better and easier for you sometimes if you're more involved, in your own choice*"	The message that individuals will have different preferences and they can change, which is ok Zoe: "*like it says you're an individual, not everyone is the same, and even you might be different between this clinic and next one, because your older or whatever, or just fancy it different and it depends*"
Renal specialist nurse	The booklet can help users know what to say or ask during consultations. "*I think people will feel a bit more confident knowing the things to go in and say, they're probably more likely to actually ask the Healthcare professional*"	The booklet can help users to be aware of their own expertise. "*nice quotes in there which is good, some stats and things ….reassurance that they're as much of an expert as the health professionals in terms of managing their own condition, yeah no I think that that's, I wouldn't have too much to add that truth be told it's good*"	The booklet encourages parents to support their child's involvement "*it covers speaking, you know, encouraging to speak to healthcare professionals and asking kind of you know about their options and their choices, encourage them to, encourages parents to start giving over that um responsibility*"	Reading others' stories can help users become more engaged " *take things on board a little bit more, kind of be a bit more open to listening Because actually "I've come through something similar to that" just taking down those barriers to them kind of engaging with it and engaging with us.*"	An empowering message that adolescents can take ownership over their care "*it, you know just gives a clear message that this is what this book is about, it's about you kind of starting to take some ownership over your care things like that, so yeah*"	A positive message about being involved in decision making. "*so I think that's really positive um I like that it's got uh lots of different quotes uh I like that it's, it's really trying to help people kind of um understand really that it's ok to kind of, to kind of get more involved in their uh Healthcare decisions* "	The booklet enables care to be tailored to users' wants and needs best. "*it's not just you know, necessarily the best healthcare option, it has to be realistic and fit in around their life, then they're gonna engage with it, then they're gonna have much better um outcomes hopefully as a result*"
Neurology specialist nurse	The booklet can help users obtain necessary information. "*They can then also use it as a way to chat through with some of the healthcare professionals to gain more information*"	The booklet can make users aware of their own expertise and decision-making confidence. they'll be like "*well I don't think there's any point in getting involved because I don't know what I'm talking about*" um and I think it just really reassures than they actually they're not going to do anything wrong	The booklet can prompt HCPs to provide further support and encourages parents to support their child's involvement I think that confident thing is really cool. And then it helps the team think: '*what can aid them make that a 5 or 6, and what they can do to support them'*"	The message that many others have similar experiences can ease isolation "*You've also got like a good bit of fact in there as well, so that will help them realise they're, it's not just them that's affected, that actually 30% is. that will hopefully help them feel like less isolated*"	The message that it is their right to be involved and they do have a say in the decisions "*I feel I would definitely use this, I think it's a nice thing for them to realise what they're allowed to do and make them more aware of their rights and that they have a voice and they are the expert, yeah*"	Positive messages around involvement, and the benefits. "*helping them realise why they need, why it would be good for them to engage because actually it works for them in the, it benefits for them if they get involved*"	The booklet helps users to identify individual preferences in order for the selection of options to be tailored to them. "*Helping them realise what's important to them, so should they be getting more involved, and what were they get out of it*"
Endocrinology specialist nurse	The booklet provides users with questions to as. "*you've giving them the wording as well, that sometimes could be easier… say: ' you can start by asking do I have a choice'*"	The booklet can improve self-efficacy by encouraging adolescents to write things down. "*Um and if somebody does need things written down because they might be forgetful or they feel better or*	The booklet reminds users that HCPs are there to support them "*I like that "the doctors are there to support you" because I think is well with long-term health conditions um there's this sort of power*	The stories are relatable and relevant to across LTCs "*there's definitely things between long-term health conditions that are relatable, you know… and you're like: "oh, that's*	The message of empowerment that they do have a choice "*I think if you're in people realise that they have got options you know sometimes that is just giving you a sense of empowerment and a sense*	Users can feel positive about involvement after reading the booklet. "*you read it and you come back to clinic more motivated by asking questions, the next time, because you've read this*"	The booklet can enable tailoring of individual option selection and helps HCPs to personalise care "*knowing that you may have a choice and treatment so finding the one that may suit you where you are in your*

		more conscientious, this can really help them"	*struggle between making people better and supporting them to live with it"*	*really relevant to the condition I've got"*	*of choice rather than something you have to do"*		*life at the minute and things they think is invaluable"*
Endocrinology specialist nurse	The booklet helps users know the questions to ask in order to gain more information. "*nice diagram they can follow, this gives them the kind of questions they can ask ok"*	Using the booklet can inform HCPs about adolescents' self-efficacy "*It's good to get an idea about their confidence around the treatment, because that's important."*	The message involvement is supported, although patients do not always have options "*Yes yes, these are good, good to be involved, yes and Health professionals want them, that's right, that's good."*	The booklet provides positive and relevant examples of involvement "*Yes, I see how this can be relevant, success stories of patients taking ownership which is important. These are some nice examples"*	The message of taking ownership of their care *Yes, I see how this can be relevant, success stories of patients taking ownership which is important.*		
Endocrinology consultant	The booklet informs users how they can find out more information. "*It's a prompt to them before they come to clinic that it…. are they aware of their options if they do have them, and if they're not aware it basically lets them know how they can find out."*	The booklet addresses concerns around saying or doing something 'wrong' "*And I think the part "well what if I say something stupid" well no you won't, there isn't anything, it's a common sentiment but if it's on your mind it's best to speak out, as it says here, this is good. I think that also our wretched education system, that's incredibly adversarial really"*	The is clear that HCPs support adolescent involvement and the booklet can help HCPs to provide further support, although health is the biggest concern "*I think so, it's saying you know it, it's good for them to be involved, it benefits them, and useful for us, as in we want them to understand everything, speak up, ask when they don't."*	The messages come from other adolescents with LTCs, which make them more relatable "*The fact they've been involved in the design is useful with the quotes and stories, gives the impression there are a lot of young people in the same boat as them, and this is coming from them."*	The message that the decisions are about the users, so it is important they are involved. "*so I think that's good, it definitely emphasizes that it's, you know it's you, it's your body, it's your say, you know don't, don't feel that you have to be told what to do by anybody, think about how you feel about it."*	The booklet highlights the benefits of involvement "*it's saying you know it, it's good for them to be involved, it benefits them, and useful for us, as in we want them to understand everything, speak up, ask when they don't"*	The booklet helps HCPs to provide personalised options, even in serious situations. "*I suppose even within that life or death there are some options, when and where they do the dialysis yup to fit in with their schedules, kind of smaller decisions, and in that way they can take a bit of onus around their treatment."*
Endocrinology consultant	The tasks and diagrams help users know how to be involved and obtain more information: "*I think it's quite a good little sort of flow chart of how to decide what, what they're going to do um, if they have a condition and they don't understand then they know that they need to ask questions".*	The booklet can make users aware of their own expertise and can improve confidence around asking questions and decision-making. "*the doctors and nurses are the experts on the condition, but they're the experts on themselves, which is, which is good. "*		Users can feel better knowing they are not alone "*it's good to say that um 30% of young people are affected by a long-term condition because that's one in three and they would feel actually it's not an unusual thing um and that might make them feel a bit um a bit better"*	The booklet prompts HCPs to allow adolescents to choose their involvement. "*If health professionals go through this with a young person as well, it might be quite a good prompt for that health professional to bear in mind that, they may not want to actually talk about this, and some things could potentially upset them.*	The booklet provides optimism and highlights the benefit of involvement "*and also kind of explains how they can benefit more by accepting it, as opposed to denying, and then benefit from being involved"*	The message that HCPs need to consider the individual as everyone experiences their conditions differently. "*Um and everybody with a long-term condition is going to experience it individually um and doctors and nurses need to take into account the individuals, not just the condition."*
HCP Focus Group	The booklet can be used as a tool to help fill in any gaps in knowledge. "*considering now that you're thinking about these options, pros and cons thinking about your own preferences and also sort of prompts, and allows you to start thinking about any questions to ask the health professionals to fill in any gaps"*		The message is clear that HCPs support adolescent involvement "*Good points, it emphasizes that us health professionals are here to support them"*	Messages coming from other adolescents are more likely to be well received. "*I like the quotes from the teenagers [Yeah] that is, you know, that just makes it for me because they've been involved, and that's are all here [Yes]"*	The message of empowerment and the benefits of taking ownership over the condition. "*It has a sort of theme about it like : 'yes, I have this condition, there's not much I can do about that, but I can at least take ownership of it so that I can get on with my normal life as much as I can despite the condition"*	The booklet provides optimism and highlights the benefit of involvement "*their involvement is for their benefit, it can help um help us to find what is actually the best treatment plan for them, something that they will adhere to because it works for them"*	The booklet enables and encourages adolescents to express their individual concerns "*this is more open which I like, because actually their concerns might be a little bit different, and instead of having it there for them already like in the 'ready steady go' booklet, they fill it in themselves so it's personal that way, more on them"*
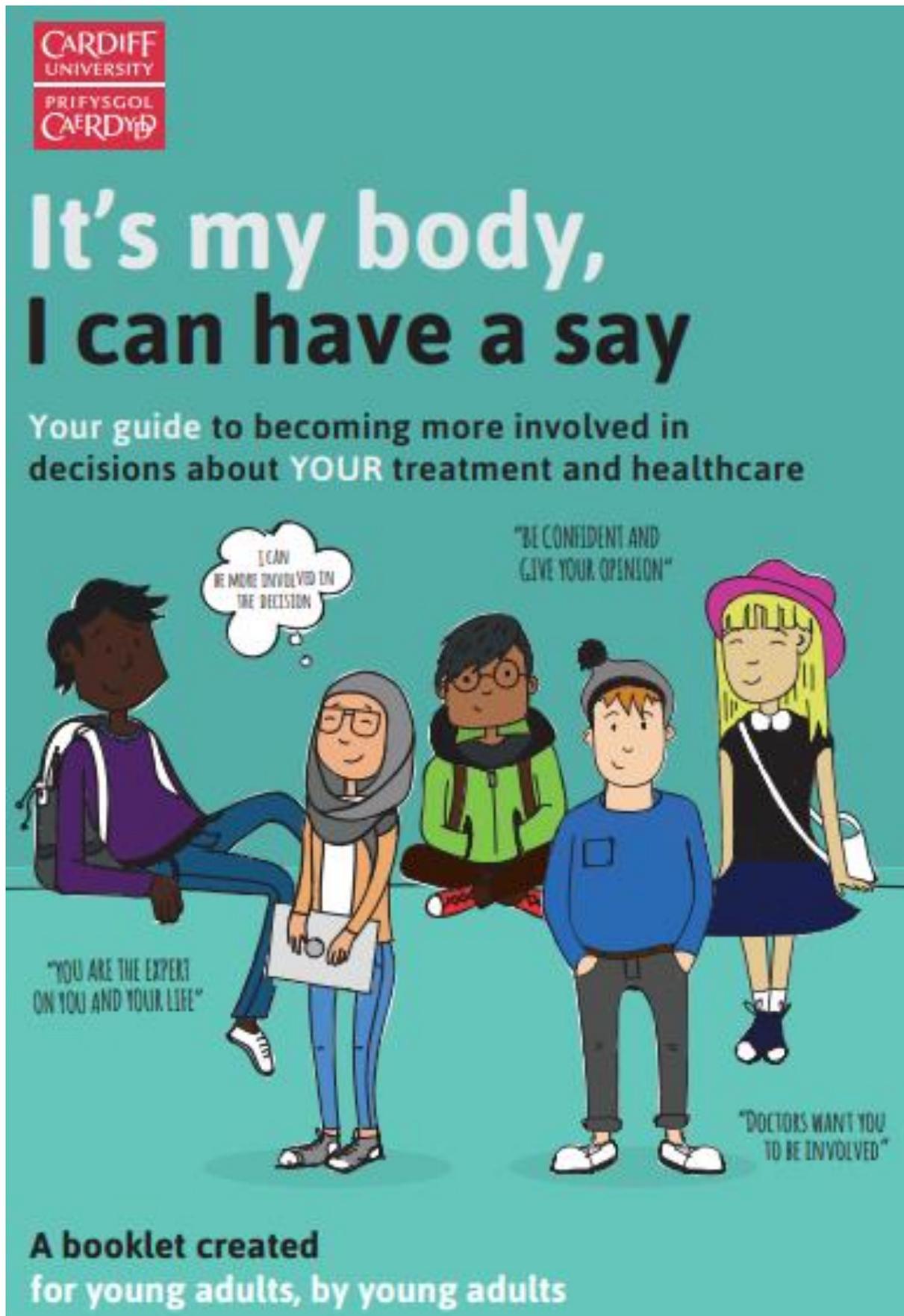
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Why should I read this booklet?

Around **30% of young people** are affected by one or more long-term conditions like eczema, asthma, epilepsy, diabetes, arthritis, kidney disease and many more.

In most of these cases, there will be choices of how **YOU can manage YOUR condition.**

When different healthcare choices are available, **your health professionals (for example doctors, nurses, psychologists, dieticians etc) want you to be involved** in these decisions, which affect **YOU and YOUR** life, and will support your involvement.

Health professionals are experts on health conditions and treatments, **but YOU are the expert on YOU and YOUR life.**

Young adults with long-term conditions say that the benefits of being involved in decisions with health professionals include: feeling more positive and confident, less **worried, and more satisfied with the decision.**

Being involved in discussions and decisions with your health professional means you can find the best treatment/ healthcare plan that really suits YOU and YOUR lifestyle.

"SPEAK UP, BE INVOLVED, TALK ABOUT IT. IF YOU'RE INVOLVED YOU'LL KNOW WHAT'S GOING ON"

You can use this booklet as a guide to help you be more involved in healthcare/treatment decisions. You can have a read through before your appointment, and go through it with your health professional.

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How can I become more involved?

You can start by taking this quiz...

1 Do you have a healthcare/treatment choice?

YES I DO → Go to question 2

I'M NOT SURE → Start by asking your health professional "Do I have a choice?"

2 Do you understand your available healthcare/treatment options?

YES, I UNDERSTAND → Go to question 3

NO, I'M UNSURE → You can ask your health professional "What are my options?"

3 Do you understand the benefits and risks of your healthcare/treatment options?

YES, IT'S QUITE CLEAR TO ME → Great, you can fill in the chart on page 5 to help you keep track

I'M NOT SURE → You can ask your health professional: "What are the benefits and risks of each option for me?" Then you can fill in the chart on Page 5

You may have some other specific questions.
Feel free to use the page at the back to write them down.

3

What is most important to me?

Here are some important self-management* issues young adults with long-term health conditions have mentioned. You can tick the one(s) which are most important to you and/or add some of your own.

○ Best fits in with my school/work

○ Fewest side-effects such as headaches/nausea

○ Least likely to make me drowsy

○ Least likely to make me gain or lose weight

○ Easiest to remember

○ Lets me get on with my normal life as much as possible

○ Least obvious to others

○ Doesn't overly interfere with my school/hobbies

○ Least effect on my mental health

○ Best at managing symptoms

○ The least painful

○ _____

○ _____

○ _____

○ _____

○ _____

○ _____

○ _____

○ _____

*Self-Management: All the actions you do to treat and manage your health

4

Weighing the options up...

Now that you know about your options, you can talk to your health professional to find which one might be best for you. You can do this by looking at the benefits and risks for each of the options, and comparing these to what is most important to YOU. You can fill this out to help you, and ask your doctor or nurse for support.

Option	Benefits +	Risks –

Now you have considered your available options and what's most important to you, which option(s) do you think might be best for you?

....

"YOU NEED TO ASSESS YOUR LIFESTYLE AND SEE WHAT FITS IN WITH THAT"

How confident do you feel that you can go through with this option?

1 2 3 4 5 6 7 8 9 10

Not confident at all   Very confident

If your score is low, you might want to consider another option.

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Here are **some questions** and concerns that young adults brought up and health professionals **answered...**

What if I make the wrong decision?

Your input is important, but you don't have to make any decisions on your own. Health professionals won't suggest options that are "wrong" for you. Many decisions can be changed if they don't work for you.

Sometimes I can't be bothered discussing things with the health professional

You don't always HAVE to be involved, but it can be helpful. Remember, health professionals WANT to help you to have the best healthcare or treatment for you. Being involved can achieve that.

What if my mum/ dad wants to be involved in the decision as well?

The last page of this booklet has been designed for you to give to your parents to read, if you like. You can ask to speak to the health professionals alone for whatever reason, if you want.

"WHAT YOU THINK MATTERS, AND DOCTORS ARE THERE TO SUPPORT YOU"
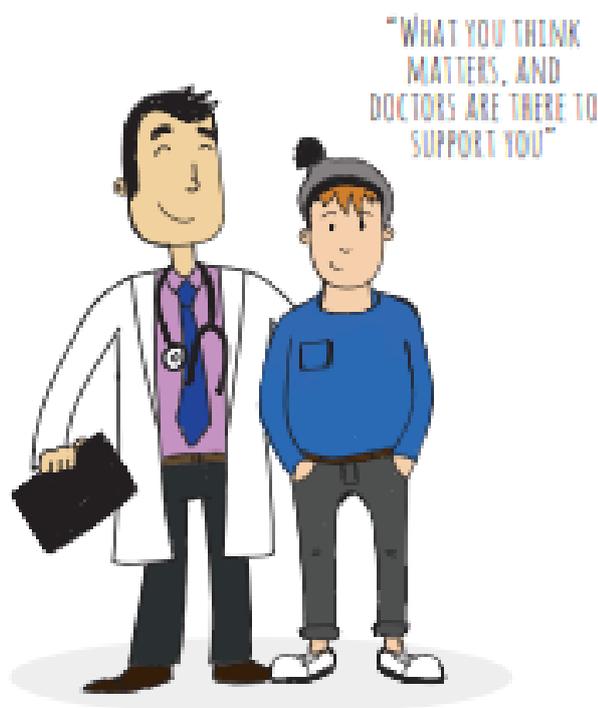
I don't always like to think or talk about my condition

Thinking or talking about a health condition that affects you can be stressful. You can be in control of how little or how much you want to know. This may change over time and that's okay. Your healthcare team are here for you when you want to talk.

I'm worried I'm going to ask or say something stupid

It's quite common to think this, in fact almost everyone does at some point. Think about it this way; if you don't ask, you won't know, and your health professionals WANT you to be fully informed about your condition and your healthcare or treatment. Also, nothing you say is stupid.

"IF YOU TELL DOCTORS WHAT YOU THINK THEN THEY'LL TAKE THAT INTO CONSIDERATION, THEN IT BEST SUITS THE DECISIONS BECAUSE THEY ARE SUITED TO YOU"

You may have more questions or concerns, feel free to bring them up with a member of your healthcare team. There is space for you to write these at the back of this booklet.

Young adults with long-term conditions speak about their experiences being involved in decisions with healthcare profressionals...

"HAVING A SAY HELPS YOU LEARN TO LIVE WITH YOUR CONDITION IN A WAY THAT YOU CAN, IN THE BEST WAY POSSIBLE"

"I was diagnosed with Type 1 diabetes when I was a baby. I was injecting insulin up to 5 times a day. I didn't like having to leave class to inject, and felt awkward doing it in front of my friends, so I sometimes missed injections. I brought this up with my doctor, and we discussed the option of trying an insulin pump. I wasn't sure at first because I met a guy who had one, and he didn't get on with it. But we decided I would give it a go, and it turned out to be a really good option for me. I was glad to have a say in that decision.

Rhys, aged 15

I was diagnosed with epilepsy 6 years ago. Last year, I had to change medications because I was having more seizures than before, I think it might have been due to the stress of GCSEs. I didn't think changing medications at this time was suitable personally, but I wasn't really involved in that decision because I was feeling really tired during the appointment, and preoccupied with my exams. It didn't really turn out well, and at the next appointment I spoke with my consultant and we decided to change again. I'm the one taking the tablets, so I think it's important that I'm involved in deciding if I actually wanna go on a certain medication or not. It was much better that I was involved in the decision of coming off the one and starting a new one, and I was happy about that.

Aamaal, aged 17

I've had arthritis for 2 years. At first, I felt quite nervous talking with the doctors and nurses, and would rather my parents do it for me. But then I realised it's better for me to participate because it's about me. It could affect my school, or other parts of my life, like playing guitar, and my parents didn't always get it right. Now I try to ask as many questions as I can, try to get myself more involved, and speak to the doctor myself instead of getting somebody else to speak for me. When I ask questions, the doctors answer them, they don't mind me speaking, they like that I'm involved, and I feel like I have a say"

Carys, aged 16

"DON'T BE AFRAID TO SPEAK OUT/ASK QUESTIONS"

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Parents' section

Feel free to give this section to your mum/dad/guardian to have a read.

The purpose of this booklet is to encourage and support your daughter/son to be more involved in discussions and decisions about their healthcare or treatment.

NHS bodies and patient organisations actively support the involvement of patients in these decisions, and believe it is beneficial to them and their healthcare needs.

There are many benefits of your daughter/son's involvement in the discussions and decisions about their healthcare such as; increased knowledge, confidence, and selecting care or treatment that is best suited to them.

You can help by supporting you daughter/son's involvement, encouraging them to ask and answer questions, voice preferences and speak directly to the health professionals. You can help them to prepare and remember the questions they want to ask using the next page.

They may like to speak to the health professional about something on their own, which is perfectly fine, and is good practice for when they're older.

"NOBODY ELSE KNOWS WHAT IT'S LIKE NOW APART FROM YOU, SO HOW'S A DOCTOR GOING TO MAKE THAT DECISION FOR YOU?"

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Your questions...

**Scan the code below
to watch the video...**

**A booklet created
for young adults by young adults**