Engaging care home residents in research: identification of barriers and facilitators to inclusion and the development of a communication support intervention

(The ENGAGE study)

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My close family and friends will be happy to know that I've now pretty much exhausted the degrees I can get and it's time for me to get a *"proper"* job.

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Summary

Care home residents are an underrepresented population in research, despite often experiencing poorer health and having the most complex care needs. As a result of this underrepresentation, relevant research evidence may not be generalisable to those who require it the most.

This mixed-methods doctoral thesis explores how care home residents can be better engaged in research. Patient and Public Involvement (PPI) was integral to the project and considered throughout each stage.

Through a scoping review, barriers and facilitators to the inclusion of care home residents were identified which included both practical and ethical factors at different system levels. Recommendations for researchers about overcoming the challenges of including care home residents in research were developed as an output from this review.

Informed by scoping review findings, a survey and interview study were conducted. These explored stakeholders' views about barriers and facilitators to care home residents' inclusion in research, their views about encouraging early discussions about residents' preferences about research participation and the facilitation of advance planning for research.

The findings suggested that poor communication between stakeholders has a large impact on the sharing of research opportunities and residents' being able to effectively share their preferences about their own research participation. By facilitating opportunities for care home residents to share their views and wishes about research it may be possible to improve inclusion.

Using established intervention development methods, an intervention was adapted and developed to support and facilitate early discussions about research participation preferences with care home residents. The findings will support opportunities for care home residents to participate in research, have their voices heard, and receive better quality evidence-based care in the future.

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List of abbreviations used

ACP – Advance Care Planning
ARP – Advanced Research Planning
BSG SIG – British Society of Gerontology Special Interest Group
CAT – Communication Accommodation Theory
CC – Caring Conversations
CIW – Care Inspectorate Wales
CQC – Care Quality Commission
DT – Deciding Together
GP – General Practitioners
ENRICH – Enabling Research in Care Homes
HRA – Health Research Authority
HSCP – Health and Social Care Professionals
INDEX – IdentifyiNg and assessing different approaches to DEveloping compleX interventions
JBI – Joanna Brigg's institute
LTT – Let's Talk Tech
MCA – Mental Capacity Act
MRC – Medical Research Council
NHS – National Health Service
NICE – National Institute for Care Excellence
NIHR – National Institute of Health and Care Research
PCC – Population, Concept, Context
PICO – Population, Intervention, Comparison, Outcome
POA – Power of Attorney
PPI – Patient and Public Involvement
PRISMA-ScR – Preferred Reporting Items for Systematic Reviews and Meta Analyses, Scoping Review extension
PWED – People With Early Dementia
RCT – Randomised Controlled Trials
SDT – Self Determination Theory
SET – Social Exchange Theory

SIT – Social Identity Theory

SLT – Social Learning Theory

SMREC – School of Medicine Research Ethics Committee

TP – Target Population

WHO – World Health Organisation

Preface

Completing both BSc and MSc degrees in Psychology solidified my true interest in human behaviour, psychopathology, and the potential of health and social care interventions across all age groups and populations. During my undergraduate degree I volunteered on an adult psychiatric ward, and the focus of my master's degree was children's psychological disorders, alongside which I worked in a secondary school with adolescents aged 11-18. Aware that I wanted to pursue a career in research, but unsure about the focus of the research area, I took some time to work with older adults with whom I had little work experience. I spent a period of time working as a support worker in a secure older adult hospital specialising in the assessment, treatment and rehabilitation of challenging patients with neuropsychiatric disorders and acquired brain injuries. Here, I found it difficult to consider that rehabilitation and/or recovery was not an option for many of these patients due to neurodegenerative disorders such as Alzheimer's disease, Huntington's disease, and Motor Neuron disease. At a later time, I took a role as Head of Activities at a nursing and residential care facility, hoping that I could combine my creative side, theoretical knowledge, and evidence-based mindset to develop and provide meaningful activities for individual residents to improve their quality of life. However, I soon realised that the research evidence-base for the care home population was inadequate and uninspiring and felt as though I was not able to provide what I envisioned.

This thesis takes a first step in understanding why the research evidence-base for the care home resident population is limited and whether there are opportunities to improve the facilitation of research including care home residents. By identifying underlying factors that contribute to the paucity of research focusing on, and including, care home residents, I hope that interventions can be developed and successfully implemented to increase both the amount and quality of research which includes care home residents. Such evidence is urgently needed to keep both policy and practice relevant within care homes, as is apparent in other health and social care settings. Care home residents deserve to receive evidence-based, person-centred care that meets their health and social care needs and provides them with improved quality of life. This starts with understanding why residents are not included in research and how we can engage them.

Publications resulting from this thesis:

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Nocivelli, B., Wood, F., Hood, K., Wallace, C., & Shepherd, V. (2024). “Research happens a lot in other settings—so why not here?” A qualitative interview study of stakeholders’ views about advance planning for care home residents’ research participation. *Age and Ageing*, *53*(10). DOI: https://doi.org/10.1093/ageing/afae235

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Chapter 1 – Introduction

1.1 Chapter overview

Funded by a Health and Care Research Wales PhD Studentship in Social Care, the ENGAGE study is presented in this thesis. This doctoral thesis aims to achieve a comprehensive understanding about why care home residents are often excluded from taking part in research and to develop an intervention aiming to improve the inclusion of this underrepresented population in research. This chapter provides a background to the topic area and an overview of the work carried out as part of this thesis. This includes an outline of chapters reporting a scoping review, survey study, and interview study to explore the need for an intervention to support care home residents, followed by a critical analysis of relevant theories, a brief review of existing interventions and resources, and the adaptation of a complex intervention.

1.2 Background

Care homes, defined in this thesis as any long-term care facilities that provide round-the-clock care for older adults (including care homes, residential homes, and nursing homes), are settings where older people live to receive support with daily activities such as personal care, eating, and taking medication [1].

Care homes play a crucial role in providing care for older people with complex needs who require extensive care that cannot be met at home [2]. These facilities differ from other care settings because they serve older adults who are often living with more disabilities, are more cognitively impaired, and closer to the end of life [3]. Care homes are unique in that they support multiple individuals with similar needs living together for extended periods, unlike other care sectors [2].

Despite their importance, care homes have not received as much research focus as other health and social care areas.

1.2.1 Health and social care in care homes and research

Health and social care in UK care homes has been shaped significantly by various policies and research evidence. The Mental Capacity Act (MCA [4]), Care Quality Commission's Health and Social Care Act (CQC; [5]), and UK Government's Care Act [6], to name a few, have had marked impacts on the regulation of care services, emphasising the importance of ethical considerations, person-centred care, autonomy, well-being, and quality of life for those living in care homes. Further, the National Institute for Health and Care Excellence (NICE) guidelines provide evidence-based recommendations to ensure high standards of care. These are considered a standard within health and care settings and are informed by ongoing research. Examples of relevant NICE guidelines include general safeguarding for adults in care homes [7]; delirium prevention, diagnosis, and management in care homes [8]; and oral health for adults in care homes [9].

Research plays a crucial role in improving health and social care within care homes. Both the policies and care practices implemented within this setting are informed by research with the aim of improving residents' quality of life by addressing their unique care needs. A review of interventional research on resident outcomes, conducted by Li and Porock [10], highlights beneficial effects of person-centred care practices on resident quality of life, psychological and physical outcomes. Research has also identified the role of staff training in reducing avoidable hospital admissions in care home residents [11], and the role of staff training in dementia care which has been shown to significantly improve the experiences and well-being of residents living with cognitive impairment [12]. Additional examples include how research has highlighted the impact of social engagement on mental health in care home residents [13-15], the need to improve nutrition and hydration [16, 17], and the importance of improving physical health [18, 19], all of which contribute to significantly improving health outcomes, well-being, and quality of life for residents.

As we progress with technological advancements and artificial intelligence, it is likely that these can benefit care too, and research has already led to the introduction of technology in care homes. For example, the benefits of wearable monitoring devices to track health in the care of older people [20], the use of video-call technology to reduce loneliness [21], and the use of “intelligent personal assistants” to support older adults [22-24]. By incorporating new research findings into care home settings, care home residents can be provided with better personalised care and thus experience greater quality of life. This, however, can only be achieved through the inclusion of care home residents in research to ensure that findings are applicable to this population.

1.2.1.1 A call for more

The COVID-19 pandemic exposed the stark disparities in mortality and other adverse outcomes experienced by groups who are frequently excluded from research, including care home residents [25]. These under-served groups already face considerable inequalities in health, particularly with the impact of intersectionality. Intersectionality refers to interactions between different social identities (such as race, age, gender, and disability) on a micro level of individual experience to show *“interlocking systems of privilege and oppression”* at the macro social-structural level [26]. The pandemic has accelerated the need for more inclusive research to ensure that research populations are representative, and that opportunities to participate in, and benefit from, research are equitable. There is a growing requirement to ensure research is inclusive of under-served populations, including from funders such as the National Institute for Health and Care Research (NIHR) [27], and recent World Health Organisation (WHO) Guidance for Best Practices in Clinical Trials [28]. Facilitating more inclusive research for care home residents may help to address “evidence-biased” medicine, as has been identified in work investigating the impact of research regulation in vulnerable populations [29].

This doctoral thesis addresses the priority area of equality, diversity and inclusion and is aligned with wider Welsh Government policy. This project also supports the vision of ‘A Healthier Wales’ which aims for everyone in Wales to have longer, healthier and happier lives and to reduce inequalities and improve population health outcomes [30]. This is captured in the intention to create ‘an equitable system which achieves equal health outcomes for all’. Further, the new White Paper ‘Rebalancing care and support’ recognises the importance of upholding people’s rights and promoting well-being and supports social care research in Wales [31]. Exclusion from research leads to disproportionately greater evidence to inform the care of populations that are able to provide consent, affects the generalisability of research, and denies these populations the opportunity to participate. Lack of inclusion also allows a focus on traditional medical outcomes rather than outcomes such as happiness and wellbeing.

Further, the Social Services and Well-being (Wales) Act [32] emphasises a particular focus on improving the quality of care and support for adults and promoting their voice and control. Improving standards of care and residents' quality of life requires high quality research to inform evidence-based changes in practice. The Dementia Action Plan for Wales [33] also has a commitment to create more opportunities for people with dementia to participate, be involved, and engage in research activity. Additionally, the Nuffield Council on Bioethics 'Future of Ageing' report highlighted the exclusion of care home residents from research, and people with impaired capacity, who are often excluded together [34].

It is apparent that key organisations and policies including, but not limited to, ENRICH Cymru, the Welsh Government, CQC, and the WHO are placing a focus on the importance of making sure research opportunities for the care home population are equitable.

A number of organisations are working to support the implementation of these policies and inclusive research across the UK and beyond. This includes regulators who are responsible for quality of care, such as care inspectorates; wider organisations who support healthy ageing, for example the WHO; and organisations to support research infrastructure in care homes, such as ENRICH."

1.2.2 The importance of including care home residents in research

It has been estimated that by 2037, adults over the age of 65 will account for 24% of the UK population [35]. There are already an estimated 490,000 care home residents in the UK [36-38]. As a result of the ageing population, many more older adults may require the level of support provided by care homes [39]. The paucity of research evidence regarding the health and social care needs of care home residents, despite the high prevalence of cognitive impairment, co-morbidity, and polypharmacy amongst care home residents [40-42], leaves this population at risk of having their health and social care needs unmet [43].

Far less research is conducted in care homes compared to other healthcare settings in the UK [44]. Whilst the physical health needs of residents have been investigated more than their mental health needs [45], care home residents are underrepresented in research. The Nuffield Council on Bioethics has reported the potential impact of historical systematic exclusion of older adults from research, including care home residents [34]. In order for research to be successful in furthering our knowledge, informing practice, and improving quality of life, it is imperative that the study participants reflect those whom the research is intended to benefit [46]. Care home residents, like all other members of society, have the right to be included in research. Further, residents' perceived value of research is not yet fully understood. However, there is research evidence that the wider population value contributing to research [47], and that care home residents value choice [48], maintaining social connections [14, 49], and having a voice [50]. Identifying factors, related to research participation, that are important to residents may be useful to the facilitation of inclusion.

1.2.3 The underrepresentation of care home residents in research

Although the prevalence of chronic health problems and functional limitations increases with age [42], older adults are often excluded from research due to both explicit and implicit restrictions, for example age limits or decisional capacity abilities [43, 51]. Furthermore, there is an apparent lack of research which has identified appropriate research methodology and strategies for recruiting older adult populations [46].

A previous systematic review, published in 2018, identified a number of challenges to conducting research in care homes [52]. The challenges were categorised into eight main themes: facility/owner factors; resident factors; staff caregiver factors; family caregiver factors; investigator factors, ethical/legal factors; methodological factors; and budgetary factors. The reasons for the exclusion of care home residents are multi-factorial, including structural inequalities from less research infrastructure and research capacity, a reduced research-orientated culture, and individual resident-related factors, such as cognitive impairment [52]. Reference to UK based studies or resident-related challenges within this review were primarily nested within a larger study, which limits the application and transferability of findings to UK care homes. This review, and other available international literature reporting challenges to conducting research in care homes, is limited due to the fact that care homes, care provision, and care home residents differ considerably between different countries [53, 54]. Further research is also needed to explore these challenges with a focus on care home residents themselves. This will enable greater opportunities for research inclusion for residents, subsequently allowing them to have their voices heard, and receive quality, evidence-based care in the future [55].

Care homes are less research active than National Health Service (NHS) settings, have access to less research training and support, and may benefit from interventions to support the development of an environment where opportunities for residents to participate are integrated into care [44]. Differences in research opportunities for older adults are apparent between care homes, in-hospital, and community settings. In care homes, research is often limited due to challenges, such as those described above. It may also be likely that smaller care homes may face more difficulties in facilitating research participation compared to larger, well-resourced homes or those associated with research networks (such as ENRICH). In contrast, in-hospital research benefits from more structured environments, clinical staff, and access to specific treatments. Community-based research, which typically occurs in home settings or through primary care, can engage a broader demographic but may struggle with reaching individuals in disadvantaged areas [56]. There are established networks to support research in care homes across the UK (for example, ENRICH, ENRICH Cymru, ENRICH Scotland). However, it has been suggested that these are not designed to provide research infrastructure [57]. UK researchers discussing need to invest in the care home research infrastructure following the impact of COVID-19, have stated *“whichever country invests in such infrastructure first will be an international trailblazer”* [57]. Furthermore, within the UK, differences exist between nations with England often leading in care home research. The type and quality rating of care homes also influence research inclusion, as higher-rated homes with more resources and staff are more likely to facilitate research than homes with lower ratings or those under financial strain [58]. Ultimately, the ability to participate in research is deeply influenced by institutional capacity, resources, and regulatory support, which differ substantially within and across regions.

One of the additional challenges in involving residents in research is the high prevalence of conditions such as dementia which results in around 70% of residents lacking capacity to provide consent to take part in research [59]. Under the MCA in these situations, a family member will be consulted to make a decision about their participation based on the resident's wishes and preferences about taking part [4]. The MCA differentiates between wishes and preferences with wishes encompassing an individual's feelings about a matter and preferences referring to likes and dislikes. Residents without a family member to act as consultee may require an alternative decision-maker – usually a nominated member of the care team – to represent the resident's wishes and preferences [29]. Knowing the resident's wishes may help families and staff acting as consultees in the event of a loss of capacity [60]. However, discussions with older people about their wishes and preferences about research, including in the event of a loss of capacity, are rare and there are currently no legal mechanisms for prospectively appointing who acts as 'consultee' [61]. Furthermore, advance planning procedures are available in many areas of life including the documentation of financial wishes and will writing, and Advance Care Planning (ACP) which offers individuals the chance to clarify their healthcare preferences and benefit from the autonomy this control may bring [62]. According to the Gold Standards Framework for end-of-life care [63], ACP is recognised internationally and is consistent with the MCA in England and Wales [4]. Although, despite being widely advocated for, ACP and other advance planning procedures have had limited uptake generally and face implementation challenges within the care home setting [64]. Internationally ACP has demonstrated significant benefits for older people in improving end-of-life care and outcomes for those with dementia and their cares, reducing hospital admissions, and enhancing patient and family satisfaction by ensuring that care aligns with personal values [65, 66]. Related to the international literature focusing on ACP in care homes, researchers suggest that more evidence is required to support the effectiveness of ACP tools in care homes [67], as well as a need to improve staff engagement in ACP [64, 67, 68].

It may be possible that anticipatory planning processes are able to support individuals, who are likely to experience impaired capacity to express their wishes and preferences, to share their views about research participation. Advance Research Planning (ARP) is one process suggested to honour the research wishes and preferences of individuals who may lose capacity in relation to their inclusion in research [69]. The views of different populations have been explored about the role that ARP activities may play in supporting preference-based inclusion in research, lending strong support for ARP as a mechanism for promoting autonomy [70, 71]. ARP has also been proposed as a means to overcome challenges associated with proxy decision-making for research [69, 71]. The Nuffield Council on Bioethics has long recommended the commissioning of research on the feasibility of developing a (non-binding) advance statement on research participation which could influence decisions on research participation after loss of capacity (Recommendation 18) [72]. Using elements of ARP, the facilitation of early, anticipatory discussions about future research wishes and preferences with care home residents, who are often considered vulnerable and difficult to recruit, may be possible.

1.3 Aims of this thesis

The aims of this thesis are to identify ways to engage and support care home residents to make informed decisions about participation in research and to develop an intervention to support residents' inclusion in research at a time when they may no longer have capacity to make a decision.

This will be achieved through:

1. Identifying barriers and facilitators to care home residents' participation in research, including residents who are able to provide their own consent and those whose capacity to consent is impaired, specifically by:

- identifying resident-related barriers and facilitators to including older people living in UK care homes in research
- identifying approaches to appropriately modify identified barriers
- exploring the views of care home residents, relatives, care home staff, other Health and Social Care Professionals (HSCPs) who work with care homes, and researchers about current opportunities for residents to participate in research, decisions about participation, and the barriers and facilitators to their involvement

2. Exploring care home residents', families', and staff's views about encouraging early discussions to elicit residents' preferences about research participation and facilitate advance planning for research

3. Developing a communication intervention to help care home residents discuss their preferences about future participation in research

1.4 Methodological approach

The epistemological foundation of this work is rooted in phenomenology, which suggests that knowledge is grounded in human experience with a focus on lived experienced [73]. This perspective aligns with the belief that knowledge is acquired and understood through describing and analysing experiences without preconceptions. In terms of ontology, the work adopts a constructivist position, considering that knowledge is constructed by individuals or groups through their experiences and interactions with the world, shaped by cultural, social and historical contexts [74]. The interplay between these epistemological and ontological viewpoints shapes the framework of this thesis, influencing both the methods used in this project and the conclusions drawn about how I could attempt to develop an intervention aiming to support care home residents to share their research participation wishes and preferences to influence future research inclusion and participation of this underrepresented population.

This mixed-methods project has combined evidence synthesis, survey, qualitative research, and complex intervention development and adaptation methods. A mixed-methods approach was chosen to combine the strengths of quantitative data, and the depth and context provided by descriptive qualitative data, aiming to gain a comprehensive understanding of the current project focus. The use of this approach allowed the research question to be addressed from multiple angles, important when considering the complex and multifaceted nature of the care home setting and relevant stakeholders. The flexibility and adaptability of a mixed-methods approach [75, 76] lends itself to such complexities. Further, using mixed-methods can provide methodological triangulation, strengthening the validity of results and increasing overall confidence in research conclusions [77]. The findings from the scoping review, survey and qualitative research were triangulated to inform the adaptation of an intervention. This included identifying the intended recipient and implementer of the intervention, its component(s), content and format. Established intervention development theories and frameworks, including the Medical Research Council (MRC) guidance on developing complex interventions [78] were used, including the development of a logic model to underpin the process.

Stage 1: Identifying barriers and facilitators to care home residents participating in research

1a. A scoping review of existing literature is presented using established methodology by Arksey and O'Malley [79] to identify the barriers and facilitators to involving older people living in UK care homes in research. The review focuses on influential factors at many system levels that enable or prevent residents engaging with research, and also identifies potentially modifiable barriers and facilitative approaches.

1b. Informed by the review findings, I then present a survey which was conducted with care home residents, families, care home staff, other health and social care professionals (HSCP), and researchers across the UK. Recruitment was undertaken through organisations such as Enabling Research in Care Homes (ENRICH) Cymru, and those identified from the Care Inspectorate Wales (CIW) database of care providers as well as through social media. The survey was available in both online and paper-based formats to enable participation from a broad range of participants. Care home residents were supported to participate through the provision of accessible information about the survey and the development of guidance documents. Questions were designed to explore participants’ views about current opportunities for residents to participate in research, decisions about participation, and the barriers and facilitators to their involvement. Participants were also invited to indicate if they were happy to be contacted to participate in an interview to be conducted at a later stage during in project.

Stage 2: Exploring views about advance planning for research participation by care home residents

Semi-structured interviews were conducted with 25 stakeholder participants across the UK, both in-person and virtually. The total anticipated sample size of 20-25 was based on the numbers anticipated to achieve sufficient saturation and information power (as determined by the research team) to address the research question and informed by previous similar studies conducted. Participants were recruited through the survey in Stage 1b and other routes such as research networks and social media. Participants were purposively sampled to ensure maximum variation using a sampling frame developed *a priori*. Interviews were conducted either in person or remotely (by video conferencing platform Zoom) depending on participant preference and appropriateness. The interviews explored participants’ views about residents participating in research and encouraging early discussions in order to elicit wishes and preferences and facilitate advance planning for research. Interviews were audio-recorded and transcribed verbatim. Thematic analysis [80] was used to qualitatively explore participants’ views and attitudes towards advance planning for research, including identifying barriers and facilitators and appropriate timing for these discussions.

Stage 3: Development of a communication support intervention for care home residents

The MRC [81, 82] refer to complex interventions in health and social care settings as strategies that involve multiple interacting components which aim to target various actions, behaviours, or interactions between different levels of stakeholders. Resources or tools are often developed to aid interventions according to the needs of the target population. After having explored existing interventions that could be considered in the development of a complex intervention, the newest MRC update suggests following guidance such as that from the IdentifyiNg and assessing different approaches to Developing complex interventions study (INDEX, [83]) if no appropriate interventions exist, and the ADAPT guidance [84], should a relevant intervention be identified which can be adapted for a new context.

A communication support intervention was identified and adapted to facilitate discussions with care home residents about research participation which will support informed decision-making and advance planning for research. This takes the form of a ‘toolkit’ which includes conversation guides and visual aid cards, developed to feature pictures or statements about the key concepts that were identified as relevant to decisions about participation in care home research studies. These concepts were obtained from Stages 1a, 1b and 2, the wider literature on research participation decisions, and from extensive patient and public involvement. The intervention was produced in collaboration with all stakeholders and underwent small scale piloting to explore the initial acceptability of the intervention.

1.5 Patient and Public Involvement (PPI)

“Research that is done ‘with’ or ‘by’ members of the public, not ‘to’, ‘for’, or ‘about’ them.” [85].

Patient and Public Involvement (PPI) refers to the active involvement of service users in research and has been thought to improve research development, prioritisation, conduct, and communication [85, 86]. The UK Health Research Authority (HRA [85]) states that research with PPI is more relevant, acceptable, and understandable and that research teams including PPI ultimately run higher quality studies. Further, the emphasis on collaborative working between researchers and patients has been referred to as a *"fundamental paradigm shift in health and care research",* promoting partnership in research [87].

PPI in healthcare research is supported by a compelling ethical rationale and is assumed to lead to research findings that are more aligned and applicable to the concerns of those who receive resulting evidence-based care [88]. Resources and training for PPI in research have been established by the NIHR in response to the recognition that patient and public stakeholders determine aspects of health and social care services and research [89].

Upon the commencement of this project, a PPI group was established, consisting of relevant stakeholders, including a member of care home staff, a relative of a care home resident, and an experienced researcher who is also a relative of a care home resident. During one of the later stages of the project, another PPI member was recruited who is a care home resident. Throughout the project, the contributions from this PPI group have been invaluable. Discussing the design, content, conduct, and findings of various studies within the project enabled stakeholders' voices to be heard, shape the progress of, and have an impact on the research.

1.6 Thesis overview

Chapter 2 reports a scoping review of the literature including both published articles and relevant grey literature. It includes identified barriers and facilitators to the inclusion of older people living in UK care homes in research and recommendations for researchers about how to overcome challenges of including care home residents in research. A PPI consultation formed a key stage of this review.

Chapter 3 presents a survey study undertaken as part of this thesis, exploring stakeholders' views about opportunities for older adults living in UK care homes to participate in research. PPI was incorporated into this stage of the project through the coproduction of the survey content.

Chapter 4 reports and discusses a qualitative interview study of stakeholders' views about advance research planning for care home residents. Identified themes include: 1) We're of no value to research; 2) Research is difficult; and 3) Advance planning for research – good in theory, challenging in practice. Recommendations to enhance opportunities for care home residents to express their research participation wishes and preferences are included in this chapter informed by the study findings. Initial study findings were presented to the PPI group and discussion helped to clarify and refine final themes.

Chapter 5 presents a critical discussion of relevant theories, identified through the discussion of primary data findings throughout this thesis, that might be applicable to an intervention in this field including autonomy, communication, and relationships.

Chapter 6 identifies and discusses existing interventions and resources to support decision-making about care and life choices for older adults, a critical stage to inform the development or adaptation of a complex intervention.

Chapter 7 reports the development of a complex intervention to support care home residents to communicate their research participation wishes and preferences informed by all previous stages of this thesis. PPI input was integral to this stage of the project with discussion and feedback shaping the development of intervention resources and the resulting 'toolkit'.

Chapter 8 presents a conclusion of this thesis, highlighting key findings and reflecting on their relevance to, and novel contribution to, the wider research literature. General strengths and limitations of the work are discussed, as well as its implications and possibilities for future research.

Throughout this thesis I adopted a reflexive approach and included a section in each chapter detailing my own reflections. This enabled a greater understanding about the project findings, care home context, and also my development as an academic.

Chapter 2 – Identifying barriers and facilitators to the inclusion of care home residents in research: A Scoping Review

2.1 Chapter overview

Chapter 2 presents a scoping review of the literature undertaken as part of this doctoral thesis. A version of this chapter has been published as an article: Nocivelli, B., Shepherd, V., Hood, K. *et al.* Identifying barriers and facilitators to the inclusion of older adults living in UK care homes in research: a scoping review. *BMC Geriatr* **23**, 446 (2023). An infographic containing recommendations for researchers about how to overcome some of the challenges of including care home residents in research has also been developed as an output from the findings of this scoping review. Findings of this work have been shared at academic conferences including those hosted by the British Society of Gerontology, the South West Society for Primary Academic Care, PRIME Centre Wales, ENRICH Scotland, and the International Clinical Trials Methodology. Additionally, dissemination of findings has been undertaken through online blog posts for ENRICH Cymru, Centre for Trials Research at Cardiff University, and PRIME Centre Wales.

This chapter contributes significantly to the first objective of this thesis and to the overall aim of the ENGAGE study by presenting a scoping review which identifies barriers and facilitators to the inclusion of care home residents in research. This chapter presents the initial step taken to understand the extent of the evidence available in this area and to inform the next steps of primary data collection. This chapter also reports gaps in the literature based on the included articles and discusses future research and practical implications.

2.2 Introduction

As outlined in the previous introductory chapter, the implementation of different key practices and policies in UK care homes have been largely influenced by research, which is particularly vital to informing evidence-based practice in health and social care settings. However, less research is conducted in care homes compared to other health and social care settings in the UK [44]. In recent years there has been a call for more research to include vulnerable populations, such as care home residents, who face considerable inequalities in health. The overall aim of this thesis includes the development of a comprehensive understanding about why care home residents are often excluded from participating in research and as a result are an underrepresented population. Thus, it is essential to first identify the factors which present barriers to, or facilitate, their inclusion.

Barriers have been referred to as factors that inhibit the implementation of change, and facilitators as factors that make implementation easier [90]. It is also often considered that the same factor can be both a barrier and a facilitator [91]. The importance of identifying barriers and facilitators in order to advance any research field has been stated by researchers, including those working in the development and implementation of complex health interventions [92]. Further, the identification of barriers and facilitators in research has also been seen as crucial for improving research design [93], enhancing recruitment and retention of underrepresented populations [94], improving data quality [95], and improving research equity [96]. In addition, research has suggested that barriers and facilitators often reflect broader contextual factors that affect the translation of research findings into practice [97].

2.2.1 Chapter aims and objectives

This chapter presents the first step of the ENGAGE study. In order to better understand why older adults living in care homes are often excluded, and therefore underrepresented in research, this thesis chapter presents a scoping review which aims to:

- Identify resident-related barriers and facilitators to including older people living in UK care homes in research
- Identify approaches to appropriately modify identified barriers

2.3 Methods

2.3.1 Protocol and registration

The protocol for this scoping review followed the scoping review protocol framework by Peters et al. (2022; [98]) and was published in advance of conducting the review on OSF, an open platform to support research, enabling the publication of pre-prints on the OSF website as an alternative to journal publication. The protocol can be found at: https://osf.io/fdy78.

2.3.2 Design

This review follows the scoping review methodology framework proposed by Arksey and O'Malley [79] with recommendations from updated versions of the framework by Levac et al. [99] and the Joanna Briggs Institute (JBI, [98, 100]) taken into consideration when relevant.

According to the chosen methodological framework there are six different stages to consider when undertaking a scoping review: identifying the research question; identifying relevant studies; selecting studies; charting the data; collating, summarising, and reporting the results; and consultation. Whilst the consultation stage is suggested as optional by Arksey and O'Malley, it was included in this study in order to strengthen the findings and their relevance.

The broad nature of a scoping review, as discussed by Munn and colleagues [101], was deemed the best fit for this review from which some basic concepts in the research area, as well as key sources, concepts, gaps, and the amount and nature of available literature need to be identified. This design was chosen as it was deemed most suitable given the objectives of the review in contrast to alternative methods such as systematic reviews, which place importance on carrying out a quality assessment of included articles, and are less iterative and flexible that scoping reviews [102]. Guidelines from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses, Scoping Review extension (PRISMA-ScR, [103, 104]) were also followed in this review.

2.3.2.1 Stage 1: Identifying the research question

The research question driving this scoping review was: "What are the resident-related barriers and facilitators to including older people living in UK care homes in research?"

2.3.2.2 Stage 2: Identifying relevant articles

For the purpose of consistency, the term 'articles' will be used throughout to refer to included materials (published papers, websites, protocols, blogs).

2.3.2.2.1 Eligibility criteria

The identification of relevant articles followed the Population, Concept, Context (PCC) framework (see Table 2.1.), as recommended by the JBI [98, 100]. Articles were included in the review if they: (1) included views of care home residents, residents' family members, care home staff, or researchers; (2) mentioned barriers or facilitators to inclusion, or suggestions/advice for modifying barriers or facilitators; and (3) took place in UK care home settings. In line with the broad nature of the review, no limits were placed on study design. Conference proceedings, protocols and systematic and literature reviews were excluded; however, the reference lists of review articles were searched to ensure that no key articles were missed. Only English language articles were included in this review considering the language abilities of the researcher and supervisors, as well as time and cost constraints. Searches of all sources were confined to articles published between January 2005 and the date the searches were conducted (March 2022). This time limit ensured that the literature reviewed was relevant to the Mental Capacity Act (MCA, [4]) before which the process for including people who lacked capacity to consent was not formalised. The MCA governs how incapacitated adults can be involved in research and provides for another person to be consulted for advice before an individual lacking capacity is included in the research [29]. The geographic context for the search was limited to the UK as different countries have different types of residential care for older adults. Additionally, different countries have different legal frameworks for research involving adults lacking capacity to consent.

Table 2.1 Proposed inclusion criteria for scoping review relevant to PCC framework

	Inclusion Criteria
Participants/Population	Care home residents Care home residents' relatives Care home staff Researchers
Concept	Barriers and/or facilitators to inclusion Resident-related factors
Context	UK care homes (residential homes, nursing homes, long-term care facilities)
Type of Source	Journal articles and other reports, both peer and non-peer reviewed Date of publication between 2005 and review commencement (March 2022) Published in English

2.3.2.2.2 Information sources and search strategy

Electronic database searches of: Medline, Web of Science, Scopus, CINAHL and PsychINFO, were conducted on 23-25th March 2022. Medline covers life sciences and biomedical journals. Web of Science covers a wide range of subject areas including health, life sciences, and medicine. Scopus covers a range literature across disciplines including science, social sciences, technology, medicine, and humanities. CINAHL covers nursing and allied health journals and PsychINFO covers journals in psychology and related fields.

A combination of terminologies, separated by key concepts, were tailored for each database with the help of a subject specific librarian. See Table 2.2 for search strategy.

Additionally, grey literature was investigated through unpublished literature (EthOS), whole site searches of relevant organisations (ENRICH, Alzheimers UK, British Society of Gerontology) as well as existing networks. Whole site searches were conducted using a Google search tool recommended by a consulted subject specialist librarian (‘search term:website’). The inclusion of grey literature in this review provided added value, considering available information wider than the academic literature. Additionally, this approach has proved beneficial in similar reviews [105].

Table 1.2 Proposed search terminologies to be input into each database, separated by key concept

	Key Concepts		**Search terms**
	Care homes (titles and abstracts)	OR	“care home*”, “nursing home*”, “residential home*”, “long-term care facilit*”
AND	Research (titles)	OR	“research*”, “study*”, “trial*”, “investig*, “explor*”, “observ*”
AND	Participation (titles and abstracts)	OR	“research subject*”, “research particip*”, “particip* research”, “recruit*”, “involv*”
AND	Barriers and facilitators (titles and abstracts)	OR	“barrier*”, “challeng*”, “factor*”, “facilitat*”, “perception*”, “perceive*”, “view*”, “attitude*”, “experience*”

2.3.2.3 Stage 3: Selecting articles

Screening was undertaken after having piloted implementing the eligibility criteria alongside a supervisor with a random selection of *n=15* articles. In screening level one, the title and abstract were reviewed for eligibility. During screening level two, the full article was reviewed against the eligibility criteria and advice was sought from supervisor VS for any articles where inclusion was unclear. Any disagreement about inclusion between the researcher and VS was referred to a second supervisor (FW) for discussion and resolution.

2.3.2.4 Stage 4: Charting the data

Data were extracted from the included articles according to the following fields: author(s) and year; source type; purpose; population; concept (barriers and facilitators); context; relevant author suggestions/advice for modification; and any other relevant comments.

The data charting form was taken from scoping review resources developed by the JBI (https://jbi-global-wiki.refined.site/space/MANUAL/4687579) and modified as relevant, per instruction of the JBI (see Appendix 2.1). Data charting for all included articles was completed independently by the researcher, with feedback provided by supervisors.

After further familiarisation with the articles, barriers and facilitators were extracted and the number of articles that discussed each factor was recorded.

2.3.2.5 Stage 5: Collating, summarising, and reporting the results

Following identification of the barriers and facilitators, factors were placed into categories based upon the system level to which they were related (i.e., staff-related, resident-related, care home-related, research-related). Although aiming to identify resident-related barriers and facilitators only, due to the complex interactions with other system-level factors, other intersecting and influential indirect factors were included. Each of the barriers and facilitators identified therefore fell into either direct or indirect categories, all with the potential to impact the inclusion of UK care home residents in research. Following familiarisation with the barriers and facilitators identified in the included articles, as is usual with scoping review methodology [104], the themes and sub-themes were iteratively developed through discussion with my supervisors.

2.3.2.6 Stage 6: Consultation

An online meeting was held in January 2023 with stakeholders to discuss the initial draft of the scoping review. The meeting included five participants, three of whom were PPI group members identified through Health and Care Research Wales. Perspectives shared by the stakeholder PPI members included those of care home staff, care home resident relative, and researcher.

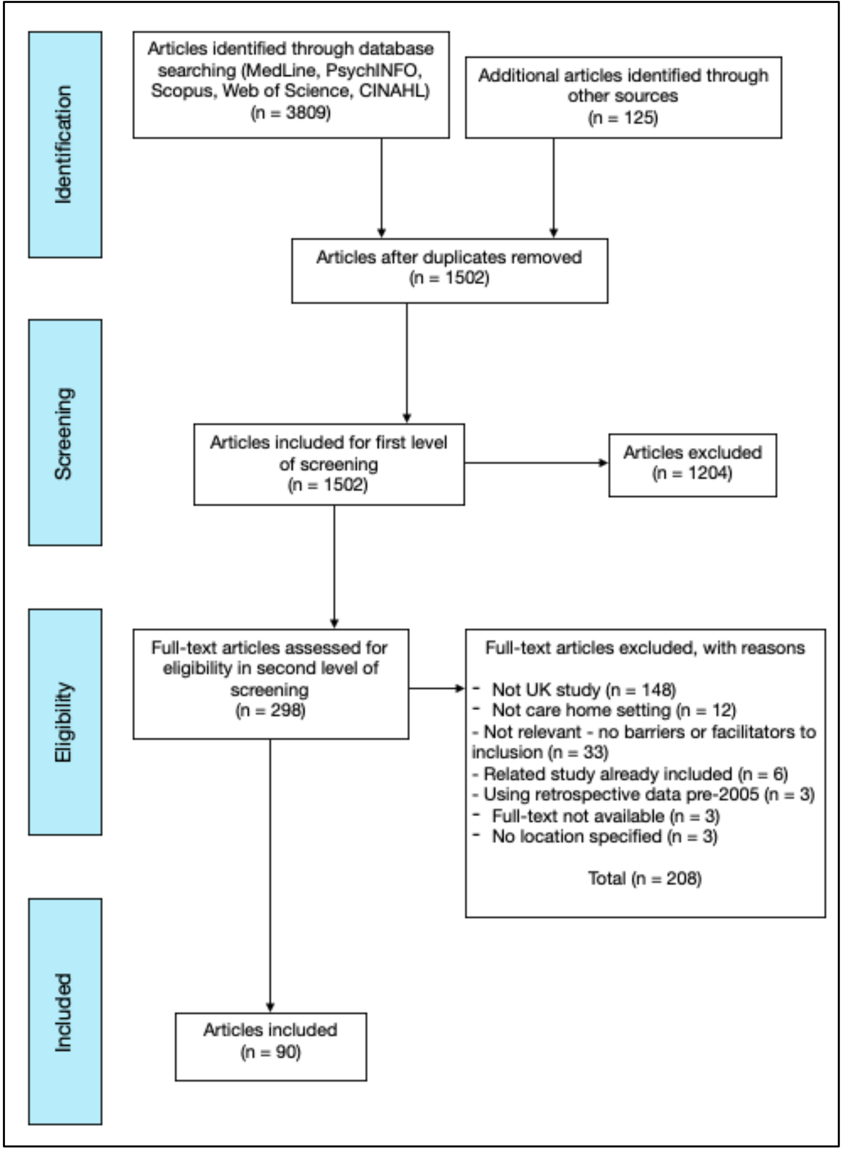
A brief PowerPoint deck of the scoping review was sent to members a week in advance with instructions to consider contributing input in the meeting based around their own expertise and perspectives. The aim of this consultation meeting was to clarify and/or validate preliminary findings. The same presentation was given in the meeting and members shared and discussed their own thoughts and perspectives, and reflections of the information presented.

2.4 Results

2.4.1 Included articles

A total of 3809 articles were identified from the database searches and a further 125 from grey literature and other sources (see Figure 2.1 for PRISMA-ScR flow chart). Following deduplication of articles, 1502 articles remained. All articles were uploaded to a reference management system, Endnote, where data management and both screening levels were completed against the eligibility criteria. After the screening of titles and abstracts during screening level one, using the predefined eligibility criteria, a total of 1204 articles were excluded, resulting in 298 articles. Following the second level of screening, 208 were excluded based on full-text review, resulting in 90 articles for data extraction.

Figure 2.1 PRISMA-ScR flow chart of article selection process



2.4.2 Article characteristics

The general characteristics of the articles included in this scoping review are reported in Table 2.3. 3809 journal articles and 125 articles from the grey literature search were initially retrieved. After both screening stages, 90 articles were selected for inclusion, 84 of which reported potential barriers and 75 potential facilitators towards inclusion of UK care home residents in research (see Tables 2.3 and 2.4). Of the included articles, 30 also included advice or suggestions for improving the inclusion of care home residents in research which can be seen in Table 2.5. See Figure 2.2 for an infographic developed as an output of this thesis chapter sharing recommendations for researchers to overcome challenges of including care home residents in research.

Table 2.3 General characteristics of included articles

Author(s)	Year	Article type	Purpose/Title	Location	Setting	Participant/Perspective	Barriers	Facilitators	Advice included
NIHR (ENRICH) [106]	2015	Interview blog	Overcoming the challenges of recruiting care homes to research	UK-wide	N/A	Researchers	✓	✓	✓
NIHR (ENRICH) [107]	2015	Interview blog	Talk to the people who know - consulting widely before starting care home research	UK-wide	N/A	Researchers		✓	✓
Aguirre et al. [108]	2012	Intervention study	Cognitive simulation therapy (CST) for people with dementia - who benefits most?	London, Essex, and Bedfordshire, UK	Care homes and community settings	113 care home residents	✓		
Airlie, Forster, and Birch [109]	2022	Randomised Controlled Trial	An investigation into the optimal wear time criteria	West Yorkshire, UK	Care homes	94 care home residents	✓	✓	

			necessary to reliably estimate physical activity and sedentary behaviour from ActiGraph wGT3X+ accelerometer data in older care home residents						
Amador et al. [110]	2014	Observational Study	Emergency ambulance service involvement with residential care homes in the support of older people with dementia: An observational study	East of England, UK	Care homes	133 care home residents	✓	✓	
Aspray et al. [111]	2006	Survey study	Low bone mineral density measurements in	Newcastle upon Tyne, UK	Care homes	392 care home residents	✓	✓	

			care home residents—a treatable cause of fractures						
Ballard et al. [112]	2018	Randomised Controlled Trial	Impact of person-centred care training and person-centred activities on quality of life, agitation, and antipsychotic use in people with dementia living in nursing homes: A cluster-randomised controlled trial	South London, North London, and Buckinghamshire, UK	Care homes	757 care home residents	✓	✓	
Barber et al. [113]	2009	Prospective study	Care homes' use of medicines study: Prevalence, causes and potential harm of medication errors	West Yorkshire, Cambridgeshire, and central London, UK	Care homes	256 care home residents		✓	

			in care homes for older people						
Bartlett, Milne, and Croucher [114]	2019	Reflective paper	Strategies to improve recruitment of people with dementia to research studies	UK-wide	N/A	Researchers	✓	✓	✓
Butler et al. [115]	2020	Randomised Controlled Trial	Effect of Probiotic Use on Antibiotic Administration among Care Home Residents: A Randomized Clinical Trial	UK	Care homes	310 care home residents	✓	✓	
Carter et al. [116]	2008	Observational Study	Chronic kidney disease prevalence in a UK residential care home population	East Kent, UK	Residential homes	250 care home residents	✓	✓	

Churcher Clarke et al. [117]	2017	Pilot intervention study	An adapted mindfulness intervention for people with dementia in care homes: Feasibility pilot study	UK	Care homes	31 care home residents	✓		
Clarke et al. [118]	2019	Interview study	A qualitative interview study comparing and contrasting resident and staff perspectives of engaging in meaningful activity in a UK care home	South London, UK	Care homes	9 care home residents, 11 care home staff members	✓	✓	
Close et al. [119]	2013	Interview study	"It's Somebody else's responsibility" - perceptions of general practitioners, heart	Northeast England, UK	Residential and care homes	17 care home residents, 8 care home staff	✓	✓	

			failure nurses, care home staff, and residents towards heart failure diagnosis and management for older people in long-term care: a qualitative interview study						
Costa, Ockelford, and Hargreaves [120]	2018	Mixed methods qualitative study	The effects of listening to preferred music on symptoms of depression and anxiety amongst elders in residential care: A qualitative, mixed methods study	London, UK	Care homes	113 residents	✓	✓	
Cunneen et al. [121]	2011	Observational study	An investigation of food provision and	East of Scotland, UK	Care homes	25 care home residents	✓	✓	

			consumption in a care home setting						
Davies et al. [122]	2014	Reflective paper	Enabling research in care homes: An evaluation of a national network of research ready care homes	UK-wide	N/A	Researchers	✓	✓	✓
Donnelly et al. [123]	2017	Qualitative study	Burden of a Remote Trial in a Nursing Home Setting: Qualitative Study	Dublin, Ireland, UK	Care homes	11 care home residents, 10 care staff members	✓	✓	
Ellmers [124]	2011	Thesis	A qualitative study of sleep and the night-time in care homes for older people	Guilford, UK	Care homes	38 care home residents, 39 care home staff members	✓		
Ellwood et al. [125]	2018	Reflective paper	Recruiting care homes to a randomised controlled trial	UK-wide	N/A	Researchers	✓	✓	

Evans et al. [126]	2011	Reflective paper	Evaluating services in partnership with older people: Exploring the role of 'community researchers’	UK-wide	N/A	Researchers	✓	✓	
Ferguson [127]	2020	Thesis	Supporting older people living in care homes: a qualitative network approach	Scottish Central Belt, UK	Care homes	36 care home residents	✓	✓	
Fleetwood-Smith, Tischler, and Robson [128]	2021	Reflective paper	Using creative, sensory and embodied research methods when working with people with dementia: a method story	UK-wide	N/A	Researchers	✓	✓	✓
Forster et al. [129]	2021	Randomised Controlled Trial	An intervention to increase physical activity in care home residents: results of	Yorkshire, UK	Care homes	152 care home residents	✓	✓	✓

			a cluster-randomised, controlled feasibility trial (the REACH trial)						
Fossey et al. [130]	2020	Qualitative study	"We should see her like part of the team": An investigation into care home staff's experiences of being part of an RCT of a complex psychosocial intervention	London, Oxfordshire, and Buckinghamshire, UK	Care homes	41 care home staff members	✓	✓	
Gallagher et al. [131]	2017	Action Research	Realising dignity in care home practice: An action research project	South of England, UK	Care homes	Care home staff		✓	✓
Gillespie et al. [132]	2015	Prospective cohort study	Antibiotic prescribing and	South Wales, UK	Care homes	279 care home residents	✓	✓	✓

			associated diarrhoea: a prospective cohort study of care home residents						
Gine-Garriga et al. [133]	2020	Interview study	Mission (im)possible: Engaging care homes, staff and residents in research studies	Glasgow, UK	Care homes	2 care home staff members	✓	✓	
Godfrey et al. [134]	2012	Qualitative study	An exploration of the hydration care of older people: a qualitative study	Southwest England, UK	Care homes	5 care home residents	✓		
Goodman et al. [135]	2013	Qualitative study	Preferences and priorities for ongoing and end-of-life care: A qualitative study of older people with	East of England, UK	Care homes	18 care home residents	✓	✓	

			dementia resident in care homes						
Goodman et al. [136]	2011	Reflective paper	Culture, consent, costs and care homes: Enabling older people with dementia to participate in research	UK-wide	N/A	Researchers	✓	✓	✓
Gordon et al. [3]	2014	Cohort study	Health status of UK care home residents: a cohort study	Nottingham, UK	Care homes	227 care home residents	✓	✓	
Graham et al. [137]	2020	Randomised Controlled Trial	A posture and mobility training package for care home staff: results of a cluster randomised controlled feasibility	Yorkshire, UK	Care homes	146 care home residents	✓	✓	

			trial (the PATCH trial)						
Griffiths et al. [138]	2019	Trial process evaluation	Barriers and facilitators to implementing dementia care mapping in care homes: results from the DCM TM EPIC trial process evaluation	West Yorkshire, Oxford, and London	Care homes	726 care home residents	✓	✓	✓
Hall et al. [139]	2019	Qualitative study	Moving beyond 'safety' versus 'autonomy': a qualitative exploration of the ethics of using monitoring technologies in long-term dementia care	Northern England, UK	Care homes	3 care home residents, 24 care home staff members, 9 relatives	✓	✓	

Hall and Beatty [140]	2014	Interview study	Assessing spiritual well-being in residents of nursing homes for older people using the FACIT-Sp-12: A cognitive interviewing study	London, UK	Care homes	17 care home residents	✓		
Hall et al. [141]	2013	Qualitative study	'It makes me feel that I'm still relevant': A qualitative study of the views of nursing home residents on dignity therapy and taking part in a phase II randomised controlled trial of a palliative care psychotherapy	London, UK	Care homes	49 care home residents	✓		

Hall et al. [142]	2011	Qualitative study	Implementing a quality improvement programme in palliative care in care homes: a qualitative study	London, UK	Care homes	11 care home residents, 26 care home staff members, 7 relatives	✓	✓	
Hall, Longhurst, and Higginson [143]	2009	Reflective paper	Challenges to conducting research with older people living in nursing homes	Southeast London, UK	Care homes	18 care home residents	✓	✓	✓
Higgins [144]	2013	Reflective paper	Involving people with dementia in research	UK-wide	N/A	Researchers	✓	✓	✓
Horne et al. [145]	2018	Reflective paper	Improving trial recruitment in care homes: the Falls IN Care Homes (FINCH) experience	UK-wide	N/A	Researchers	✓	✓	

Hsu et al. [146]	2015	Randomised controlled feasibility study	Individual music therapy for managing neuropsychiatric symptoms for people with dementia and their carers: a cluster randomised controlled feasibility study	UK	Care homes	17 care home residents, 10 care home staff members	✓	✓	
Jain et al. [147]	2021	Qualitative study	Dog-assisted interventions in care homes: A qualitative exploration of the nature, meaning and impact of interactions for older people	Southeast of England, UK	Care homes	54 care home residents	✓	✓	
Jenkins et al. [148]	2016	Reflective paper	Overcoming challenges of	UK-wide	N/A	Researchers	✓	✓	✓

			conducting research in nursing homes						
LaFrenais [149]	2015	Reflective paper NIHR blog	Understanding Care Home Research	UK-wide	N/A	Researchers	✓	✓	✓
Law [150]	2016	Thesis	Research in care homes: issues of participation and citizenship	Scotland, UK	Care homes	Researchers	✓	✓	✓
Law et al. [151]	2021	Survey study	Motivating and constraining factors for research participation in Scottish care homes	Scotland, UK	Care homes	Care home staff	✓	✓	
Law and Ashworth [152]	2022	Interview study	Facilitators and Barriers to Research Participation in Care Homes: Thematic Analysis of Interviews with	Scotland, UK	Care homes	12 care home residents, 15 care home staff members, 6 relatives, 8 researchers	✓	✓	

			Researchers, Staff, Residents and Residents’ Families						
Lee and Bartlett [153]	2021	Ethnographic study	Material Citizenship: An ethnographic study exploring object-person relations in the context of people with dementia in care homes	Southern England, UK	Residential home	15 care home residents, 16 care home staff members, 8 relatives		✓	
Livingston et al. [154]	2012	Intervention study	Improving the end-of-life for people with dementia living in a care home: an intervention study	London, UK	Care homes	Care home residents, care home staff members, and relatives		✓	
Luff et al. [155]	2015	Reflective paper	A guide to research with care homes (2015)	UK-wide	N/A	Researchers	✓	✓	✓
Maidment et al. [156]	2018	Intervention study	Medication review plus person-centred	West Midlands, UK	Care homes	108 care home residents	✓	✓	✓

			care: A feasibility study of a pharmacy-health psychology dual intervention to improve care for people living with dementia						
Maluf [157]	2017	Thesis	The social lives of older men living in care homes and the implications for their wellbeing	UK-wide	Care homes	Care home residents, care home staff members, relatives	✓	✓	
Moore et al. [158]	2017	Intervention study	Implementing the compassion intervention, a model for integrated care for people with advanced dementia towards the end of life in nursing	Northern London, UK	Care homes	9 care home residents	✓		

			homes: a naturalistic feasibility study						
NIHR [159]	2019	Blog post/interview	Helen’s Story	UK-wide	N/A	Researchers	✓		
O'Neill et al. [160]	2022	Interview study	‘Waiting and Wanting’: older peoples' initial experiences of adapting to life in a care home: a grounded theory study	UK-wide	Care homes	17 care home residents	✓		✓
Orellana et al. [161]	2019	Qualitative study using interviews and observations	Older care home residents' and their relatives' knowledge, understanding and views of shift handovers: an exploratory,	Southeast England, UK	Care homes	10 care home residents, 5 care home managers, 6 relatives	✓		

			focused-ethnographic qualitative study using interviews and observations						
Orrell et al. [162]	2007	Randomised Controlled Trial	A cluster randomised controlled trial to reduce the unmet needs of people with dementia living in residential care	London, North Wales, and Manchester, UK	Care homes	238 care home residents	✓		
Paddock et al. [163]	2019	Qualitative case study using interviews and observations	Care Home Life and Identify: A Qualitative Case Study	Greater Manchester, UK	Care homes	9 care home residents, 4 relatives, 5 care home staff members	✓	✓	✓
Parsons et al. [164]	2015	Feasibility study	Development and Application of Medication Appropriateness	Northern Ireland, UK	Care homes	15 care home residents	✓	✓	

			Indicators for Persons with Advanced Dementia: A Feasibility Study						
Patchwood, et al. [165]	2020	Qualitative study using interviews and observations	Six-month reviews for stroke survivors: A study of the modified Greater Manchester Stroke Assessment Tool with care home residents	Northwest of England, UK	Care homes	71 care home residents	✓	✓	
Perfect et al. [166]	2019	Reflective paper	Collecting self-report research data with people with dementia within care home clinical trials: Benefits, challenges and best practice	UK-wide	Care homes	Researchers	✓		✓

Powell et al. [167]	2017	Pilot parallel Randomised Controlled Trial	Pilot parallel randomised controlled trial of protective socks against usual care to reduce skin tears in high risk people: ‘STOPCUTS’	Exeter, Exmouth/Sidmouth, and Mid Devon, UK	Care homes	54 care home residents	✓	✓	
Rajkumar et al. [168]	2016	Factorial Cluster Randomised Controlled Trial	Apathy and Its Response to Antipsychotic Review and Nonpharmacological Interventions in People With Dementia Living in Nursing Homes: WHELD, a Factorial Cluster Randomized Controlled Trial	UK-wide	Care homes	273 care home residents	✓	✓	

NIHR [169]	N/A	Interview/Blog	Taking part in research – the care home perspective	UK-wide	N/A	Researchers/Care home managers	✓	✓	✓
Riazi et al. [170]	2012	Qualitative study	Quality of life in the care home: A qualitative study of the perspectives of residents with multiple sclerosis	Within 100 miles of London, UK	Care homes	37 care home residents	✓	✓	
Richardson et al. [171]	2020	Reflective paper	Research with older people in a world with COVID-19: Identification of current and future priorities, challenges and opportunities	UK-wide	N/A	Researchers	✓	✓	✓
Sackley et al. [172]	2015	Cluster Randomised Controlled Trial	An occupational therapy intervention for residents with stroke related disabilities in UK	UK-wide	Care homes	1042 care home residents	✓	✓	✓

			care homes (OTCH): cluster randomised controlled trial						
Sampson et al. [173]	2018	Prospective cohort study	Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life	Greater London, UK	Care homes	70 care home residents	✓	✓	✓
Shamshirsaz [174]	2015	Thesis	Apply QFD methodology to capture 'unheard' voices of UK care home residents and translate them into quality measurement	Peterborough and West London, UK	Care homes	15 care home residents	✓		

			targets for future improvement						
NIHR – Shepherd [175]	2020	Blog post	How care homes can support the inclusion of people with impaired capacity	UK-wide	N/A	Researchers		✓	
Shepherd et al. [176]	2015	Reflective paper	Setting up a clinical trial in care homes [176]: challenges encountered and recommendations for future research practice	UK-wide	N/A	Researchers	✓	✓	✓
Shrotri et al. [177]	2021	Prospective cohort study	Vaccine effectiveness of the first dose of ChAdOx1 nCoV-19 and BNT162b2 against SARS-CoV-2 infection in	England, UK	Long-term care facilities	10412 care home residents	✓	✓	

			residents of long-term care facilities in England (VIVALDI): a prospective cohort study						
Siddiqi et al. [178]	2016	Feasibility cluster Randomised Controlled Trial	The PiTSTOP study: a feasibility cluster randomized trial of delirium prevention in care homes for older people	UK-wide	Care homes	215 care home residents	✓	✓	✓
Simpson et al. [179]	2017	Feasibility study	The challenges and opportunities in researching intimacy and sexuality in care homes accommodating older people: a feasibility study	Northwest England, UK	Care homes	6 care home residents and their partners, 16 care home staff members	✓	✓	

Smith et al. [180]	2019	Reflective paper	Encouraging managers of care homes for older adults to participate in research	UK-wide	N/A	Researchers	✓	✓	
Stow et al. [181]	2018	Cluster randomised feasibility trial	Care home resident and staff perceptions of the acceptability of nutrition intervention trial procedures: a qualitative study embedded within a cluster randomised feasibility trial	UK-wide	Care homes	4 care home residents, 12 care home staff members	✓	✓	
Subramaniam, et al. [182]	2014	Randomised Controlled Trial	Life review and life story books for people with mild to moderate dementia: A randomised controlled trial	North Wales, UK	Care homes	23 care home residents	✓		

Towers et al. [183]	2019	Cross-sectional study	A cross-sectional study exploring the relationship between regulator quality ratings and care home residents' quality of life in England	Southeast England, UK	Care homes	293 care home residents	✓	✓	
Tzouvara et al. [184]	2016	Reflective paper	Lessons learned from recruiting nursing homes to a quantitative cross-sectional pilot study	UK-wide	N/A	Researchers	✓	✓	
Underwood et al. [185]	2013	Randomised Controlled Trial	Exercise for depression in care home residents: a randomised controlled trial with cost-effectiveness analysis (OPERA)	Northeast London, Coventry, and Warwickshire, UK	Care homes	891 care home residents	✓	✓	

Usman et al. [186]	2019	Prospective cohort study	Measuring health-related quality of life of care home residents: comparison of self-report with staff proxy responses	East Midlands, England, UK	Care homes	117 care home resident and staff matched pairs	✓	✓	
Watkins et al. [187]	2017	Qualitative interview study	Exploring residents' experiences of mealtimes in care homes: A qualitative interview study	Southwest England, UK	Care homes	11 care home residents	✓	✓	✓
Wenborn et al. [188]	2013	Cluster Randomised Controlled Trial	Providing activity for people with dementia in care homes: A cluster randomised controlled trial	London, UK	Care homes	210 care home residents	✓	✓	✓
Whelan et al. [189]	2013	Reflective paper	Impact of the demand for 'proxy assent' on	UK-wide	N/A	Researchers	✓		

			recruitment to a randomised controlled trial of vaccination testing in care homes						
Windle et al. [190]	2018	Mixed-methods longitudinal investigation	The impact of a visual arts program on quality of life, communication, and well-being of people living with dementia: A mixed-methods longitudinal investigation	Northeast England, UK	Care homes	48 care home residents	✓	✓	
Wood et al. [70]	2013	Qualitative study	Consent, including advanced consent, of older adults to research in care homes: a qualitative study of	South Wales, UK	Care homes	14 care home residents, 14 relatives, 10 GPs, care home staff	✓	✓	

			stakeholders’ views in South Wales						
Wylie et al. [191]	2017	Pilot randomised controlled trial	Podiatry intervention versus usual care to prevent falls in care homes: pilot randomised controlled trial (the PIRFECT study)	East of Scotland, UK	Care homes	43 care home residents	✓	✓	✓
Zamir et al. [21]	2018	Implementation study	Video-calls to reduce loneliness and social isolation within care environments for older people: an implementation study using collaborative action research	Devon and Cornwall, UK	Care homes	8 care home residents	✓	✓	

2.4.3 Barriers and facilitators to the inclusion of UK care home residents in research

Alongside resident-related factors that directly affected the inclusion of care home residents, a number of indirect factors were identified which were viewed as important and influential and so warranted inclusion. Factors directly affecting inclusion refers to factors which are solely related to and impact individual residents, such as cognitive impairment, whereas indirect factors to inclusion refer to factors that residents have no control over and may even be unaware of, such as gatekeeping.

The complex barriers and facilitators to the inclusion of UK care home residents in research were synthesised into seven thematic categories: (1) research design; (2) understanding and beliefs about research (resident and care home staff); (3) communication; (4) relationships; (5) eligibility criteria (resident and care home); (6) preference-based decisions; and (7) care home staff and environment.

2.4.3.1 Research design

The design of the study was discussed as both a barrier and facilitator to the inclusion of care home residents in research. The use of existing networks during recruitment was a common approach and resulted in being an indirect facilitator to the inclusion of care home residents in research [3, 21, 106, 107, 110, 116, 125, 127, 130, 136, 147, 156, 163, 167, 170, 173, 179, 180, 187, 191]. However, the sole use of existing networks, including ‘research ready’ care homes for example, may also present an indirect barrier for the inclusion of UK care home residents in research [110, 147, 167, 179], as the approach excludes those care homes that are not within those networks.

The piloting of the recruitment process was mentioned in two of the included articles and poses a potential indirect facilitator to inclusion [107, 125]. Piloting was considered helpful in terms of identifying challenges which can be addressed prior to recruitment. Researcher flexibility, including tailoring research methods and/or requirements to specific care home settings and/or residents was discussed in a number of included articles [70, 106, 114, 130], as was the importance of researchers experience of conducting research in care home settings [148].

The research design choice of relying on care home staff to determine study eligibility was commonly reported by the included articles, posing a potential barrier to the inclusion of care home residents in research through issues of recruitment bias [3, 118, 123, 124, 127, 135, 140, 143, 155, 158, 160, 161, 164, 169, 174, 185, 187, 191]. Further, the burden, on care home residents and staff, of the chosen methods of data collection, including monitoring periods were discussed in included articles [21, 70, 109, 114, 176], as were designs which require significant time and environmental requirements [122, 148, 184], such as private space, all of which present potential barriers to the inclusion of care home residents in research.

2.4.3.2 Understanding and beliefs about research

Resident. A number of the included articles discussed barriers around residents' general lack of interest in participating in research, as well as initial interest and then disengagement [70, 122, 123, 143, 166, 167, 173, 179, 181]. Resident understanding about what research is, what is required of them, and other related concerns also posed a potential barrier for inclusion [150-152]. Highlighting to residents the potential benefits of research was the most common facilitator discussed in the included articles [70, 114, 122, 132, 133, 192], followed by residents' altruism [114, 150].

Care Home Staff. A lack of understanding by care home staff and negative beliefs about research, including underlying research motives were discussed in a number of included articles [21, 123, 136, 138, 142, 148, 163, 184]. Ensuring accurate understanding about the nature of the research being conducted, and staff having positive beliefs about the research was reported in a number of included articles and offered a potential indirect facilitator to resident inclusion [130, 138, 152].

2.4.3.3 Communication

The approach to presenting research information to potential participants was discussed in some of the included articles, posing both a potential barrier and facilitator to the inclusion of care home residents in research [123, 150]. Communicating information to residents in an accessible, tailored manner was considered to be a direct facilitator to resident inclusion [109, 122, 123, 128, 136, 143, 150]. Providing clear and honest information from the start, as well as facilitating positive, clear and consistent communication with all stakeholders were factors also considered to be helpful [70, 106, 107, 114, 122, 130, 133, 142, 149-152, 155, 169, 180, 184]. One included article discussed the importance of effective communication ensuring true understanding [152]. Difficulties in communication, including those caused by cognitive impairment and loss of verbal skills were reported as direct barriers for inclusion in research for care home residents [150, 192]. Fluctuations in resident capacity and in resident mood also posed challenges to participation in research [70, 143, 166, 181]. Poor communication between care home staff, researchers, and relatives posed another potential indirect barrier to inclusion [70, 142], as did poor communication between the research team and staff [106, 125, 138, 150, 180, 184, 192].

2.4.3.4 Relationships

The importance of building rapport between the research team, residents, care home staff and relatives was discussed in many included articles. The importance of researchers spending time at care homes before study commencement was commonly discussed and is a potential facilitator to inclusion [127, 128, 150, 153, 157, 163, 169, 184]. The benefits of developing positive relationships with gatekeepers, such as care home managers, were discussed also [155, 176].
The use of a collaborative working style between the research team, residents, staff, and relatives was proposed as a potential facilitator to the inclusion of care home residents in research [109, 114, 122, 123, 126, 128, 131, 133, 135, 136, 143, 145, 147, 149, 155, 190]. Providing personalised feedback and a feeling of inclusivity for

care home staff and residents was also mentioned as a positive experience and may indirectly facilitate resident inclusion in research [130, 180].

2.4.3.5 Eligibility criteria

Eligibility of residents. Strict resident eligibility criteria were the most common direct resident-related barriers to inclusion, with exclusion often based on age limits [21, 109, 110, 115, 119, 124, 125, 129, 134, 137, 139, 141, 143, 146, 158, 162-164, 167, 173, 177, 185-188, 191] and comorbidity (e.g., learning disability, terminal illness, cognitive impairment) being the most common [3, 108, 109, 115, 117, 120, 121, 123, 124, 129, 134, 141, 143, 146, 150, 152, 156, 162, 172, 174, 177, 178, 182, 183, 185, 186, 188, 191, 192]. The exclusion of participants who lacked the capacity to consent to participation, with no option of utilising a personal consultee, were reported [109, 116, 117, 127, 134, 135, 140, 160, 162, 163, 170, 181, 182, 187, 191] as well as those who did not have an adequate ability to communicate, understand, or engage in conversation [108, 117, 136, 170, 174, 178, 185, 187]. The requirement of a clinical diagnosis of dementia (as opposed to a likely diagnosis) was a potential barrier in a number of included articles [108, 112, 117, 156, 158, 162, 164, 168, 173, 178, 182, 188], as was the requirement to understand and communicate in English [108, 117, 125, 127, 136, 139, 140, 143, 150, 152, 156, 163, 174, 178, 182, 185]. The requirement of a study partner posed a potential barrier was discussed in two articles [114, 182].

The allowance of another person being able to consent to participation on behalf of a resident who lacks capacity to consent, i.e., a personal consultee, was the most frequently mentioned potential facilitator to inclusion in the included articles [3, 109-111, 113, 115, 118, 119, 121, 123, 128, 129, 132, 136, 137, 139, 144-146, 148-150, 152-154, 156, 157, 164, 168, 172, 175, 178, 183, 185, 186, 188, 190, 192]. Additionally, utilising minimal eligibility criteria was also found to be a potential facilitator to the inclusion of care home residents in research [110-114, 116, 118-120, 132, 147, 157, 170-172, 190].

Eligibility of care homes. The presence of strict care home eligibility criteria proposed an indirect resident-related barrier to inclusion for UK care home residents. Most commonly reported were the need to meet criteria for the location and type of care home [3, 110, 124, 125, 127, 136, 150, 156, 157, 178] and [110, 112, 124, 125, 127, 136, 150, 152, 156, 168, 173, 187], respectively. The size of care homes was another common eligibility criteria [115, 125, 136, 156, 157, 164, 187], as were the rating/quality of care homes, as awarded by organisations such as the Care Quality Commission (CQC) [112, 125, 130, 136, 150, 152, 161, 173, 187]. Care homes who were requiring special support from their local authorities were also reported to be excluded from some research [112, 168].

2.4.3.6 Preference-based decisions

Residents' expressions of perceptions of disempowerment, including lack of autonomy, confidence, apathy and having worries about research participation were discussed in a number of included articles and posed barriers relating to participation in research [118, 123, 135, 136, 143, 150, 168]. Further, a lack of awareness about research participation opportunities and being overlooked with regards to participation posed potential barriers to inclusion [114, 150, 159]. Providing residents with the opportunity to participate in research, by directly asking them, is a potentially empowering facilitator to inclusion which was discussed in one article [150]. Relatives' unwillingness to take part, or in cases where a personal consultee option was available, refused to consent or make a decision regarding resident participation, presented a barrier to inclusion [21, 70, 115, 143, 145, 149, 189], as did the impact of what article authors referred to as "gatekeeping" and "overprotective relatives" [70, 119, 122, 124, 126, 144, 150, 155, 171, 176, 192]. The impact of external influences was discussed in included articles and were potential indirect barriers to research inclusion. The impact of research ethics committees was discussed in one article [148], as was the impact of legal frameworks [189].

2.4.3.7 Care home staff and environment

Factors relating to the care home, including the care home staff and the care home environment created both direct and indirect barriers and facilitators to the inclusion of care home residents in research. Providing and communicating the benefits and incentives of research participation to care home staff was mentioned in a number of included articles and may provide an indirect facilitator to research inclusion [107, 114, 130, 172, 180, 184]. Care home staff interest, support, and engagement in research were reported to provide an indirect facilitator to research inclusion [21, 107, 109, 114, 122, 130, 138, 143, 151, 175, 183, 184, 188], as did care home manager interest specifically [113, 117]. A number of included articles also discussed the benefits of providing staff training and opportunities for knowledge development as part of the research process [107, 122, 130, 151, 181].

The impact of research on care home staff was the most common indirect resident-related barrier to inclusion, with time pressure felt by care home staff and workload factors most commonly discussed [106, 123, 127, 130, 132, 133, 148, 151, 152, 155, 166, 180, 184], followed by high staff turnover [21, 114, 122, 133, 138, 148, 149, 155, 180, 184]. Staff disinterest, engagement and negative attitudes towards research, were the next most frequently discussed [21, 123, 130, 136, 138, 143, 148, 152, 192]. A lack of confidence in facilitating research was discussed in two included articles [123, 157]. Perceived lack of support from the care home manager [133, 138, 150, 152, 163] and the culture within care homes [114, 124] were also discussed in included articles. Conversely, manager support for the study was reported as an indirect facilitator [108, 133, 138, 150, 183, 192].

Limitations of the care home environment, including a lack of private space in which to consent residents and collect data, and disruption of daily routines caused by research, posed a barrier to resident inclusion [123, 124, 133, 143, 150, 155, 163, 166, 169, 192]. However, in a number of included articles, it was shown that the care home environment can be used to facilitate research participation, such as positive use of spaces that were chosen by residents, for example residents' own bedrooms, to conduct research which facilitates privacy [70, 120, 135, 150, 155]. However, residents' ability to have their own private room is not always available in all care homes.

Furthermore, the culture of care homes, specifically care homes with a culture of inclusiveness, was reported as a facilitator to the inclusion of residents in research [136].

Table 2.4 Identified barriers and facilitators to the inclusion of UK care home residents in research

Barriers	**Facilitators**
Research Design	
The sole use of existing networks, including 'research ready' care homes for example [110, 147, 167, 179]. Care home staff responsible for choosing who they deemed as eligible to participate [3, 118, 123, 124, 127, 135, 140, 143, 155, 158, 160, 161, 164, 169, 174, 185, 187, 191]. The research burden of the chosen methods of data collection, including monitoring periods were discussed in included articles [21, 70, 109, 114, 176]. Designs which require significant time and environmental requirements such as private space [122, 148, 184].	The use of existing networks during recruitment [3, 21, 106, 107, 110, 116, 125, 127, 130, 136, 147, 156, 163, 167, 170, 173, 179, 180, 187, 191]. Piloting of the recruitment process [107, 125]. Researcher flexibility, including tailoring research methods and/or requirements to specific care home settings and/or residents [70, 106, 114, 130]. Researcher experience in care home settings [148].
Understanding and beliefs about research	
Resident Residents' general lack of interest in participating in research, as well as initial interest and then disengagement [70, 122, 123, 143, 166, 167, 173, 179, 181].	*Resident* Highlighting the potential benefits of research [70, 114, 122, 132, 133, 192]. Residents' altruism [114, 150].

Barriers	Facilitators
Resident misunderstanding about what research is, what is required of them, and other related concerns [150-152]. *Care home staff* Lack of care home staff understanding and negative beliefs about research, including underlying research motives [21, 123, 136, 138, 142, 148, 163, 184].	*Care home staff* Ensuring true understanding about the nature of the research being conducted, and staff having positive beliefs about the research [130, 138, 152].
Communication	
The approach to presenting research information to potential participants [123, 150]. Difficulties in communication, including those caused by cognitive impairment and loss of verbal skills [150, 192]. Fluctuations in resident capacity and in resident mood [70, 143, 166, 181]. Poor communication between care home staff researchers, and relatives [70, 142]. Poor communication between the research team and staff [106, 125, 138, 150, 180, 184, 192].	The approach to presenting research information to potential participants [123, 150]. The communication of research information to residents in an accessible, tailored manner [109, 122, 123, 128, 136, 143, 150]. Providing clear and honest information from the very start, as well as facilitating positive, clear and consistent communication with all stakeholders [70, 106, 107, 114, 122, 130, 133, 142, 149-152, 155, 169, 180, 184].
Relationships	
	Researchers spending time at care homes before study commencement

Barriers	**Facilitators**
	[127, 128, 150, 153, 157, 163, 169, 184]. The benefits of developing positive relationships with gatekeepers, such as care home managers, were [155, 176]. The use of a collaborative working style between the research team, residents, staff, and relatives [109, 114, 122, 123, 126, 128, 131, 133, 135, 136, 143, 145, 147, 149, 155, 190]. Providing personalised feedback and a feeling of inclusivity for care home staff and residents [130, 180].
Eligibility criteria	
Resident Age limitations [21, 109, 110, 115, 119, 124, 125, 129, 134, 137, 139, 141, 143, 146, 158, 162-164, 167, 173, 177, 185-188, 191]. Comorbidity (e.g., learning disability, terminal illness, cognitive impairment) [3, 108, 109, 115, 117, 120, 121, 123, 124, 129, 134, 141, 143, 146, 150, 152, 156, 162, 172, 174, 177, 178, 182, 183, 185, 186, 188, 191, 192]. The exclusion of participants who lacked the capacity to consent to	*Resident* The allowance of another person being able to consent to participation on behalf of a resident who lacks the capacity to consent, i.e., a personal consultee [3, 109-111, 113, 115, 118, 119, 121, 123, 128, 129, 132, 136, 137, 139, 144-146, 148-150, 152-154, 156, 157, 164, 168, 172, 175, 178, 183, 185, 186, 188, 190, 192]. Utilising minimal eligibility criteria [110-114, 116, 118-120, 132, 147, 157, 170-172, 190].

Barriers	Facilitators
participation, with no option of utilising a personal consultee [109, 116, 117, 127, 134, 135, 140, 160, 162, 163, 170, 181, 182, 187, 191]. Exclusion of those who did not have an adequate ability to communicate, understand, or engage in conversation [108, 117, 136, 170, 174, 178, 185, 187]. The requirement of a clinical diagnosis of dementia [108, 112, 117, 156, 158, 162, 164, 168, 173, 178, 182, 188]. The requirement of an ability to understand and communicate in English [108, 117, 125, 127, 136, 139, 140, 143, 150, 152, 156, 163, 174, 178, 182, 185]. The requirement of a study partner [114, 182]. *Care home* Location of care home [3, 110, 124, 125, 127, 136, 150, 156, 157, 178]. Type of care home [110, 112, 124, 125, 127, 136, 150, 152, 156, 168, 173, 187]. Size of care homes [115, 125, 136, 156, 157, 164, 187].	

Barriers	Facilitators
Rating/quality of care homes, as decided by organisations such as the CQC [112, 125, 130, 136, 150, 152, 161, 173, 187]. Care homes receiving special support from their local authorities were excluded in some included studies [112, 168].	
Preference-based decisions	
Residents' expressions of perceptions of disempowerment, including lack of autonomy, confidence, apathy and having worries about research participation [118, 123, 135, 136, 143, 150, 168]. A lack of awareness about research participation opportunities and being overlooked with regards to participation [114, 150, 159]. Relatives' unwillingness to take part, or in cases where personal consultee option was available, refused to consent or make a decision regarding resident participation, [21, 70, 115, 143, 145, 149, 189].	Providing residents with the opportunity to participate in research, by directly asking them [150].

Barriers	**Facilitators**
The impact of gatekeeping and overprotective relatives [70, 119, 122, 124, 126, 144, 150, 155, 171, 176, 192]. The impact of research ethics committees [148]. The impact of legal frameworks [189].	
Care home staff and environment	
Time pressure felt by care home staff and workload factors [106, 123, 127, 130, 132, 133, 148, 151, 152, 155, 166, 180, 184]. High staff turnover [21, 114, 122, 133, 138, 148, 149, 155, 180, 184]. Staff lack of interest, engagement and negative attitudes towards research, participation, and facilitation [21, 123, 130, 136, 138, 143, 148, 152, 192]. A lack of confidence in facilitating research was discussed in two included articles [123, 157]. Perceived lack of support from the care home manager [133, 138, 150, 152, 163]. The culture within care homes [114, 124].	Providing and communicating the benefits and incentives of research participation to care home staff [107, 114, 130, 172, 180, 184]. Care home staff interest, support, and engagement in research [21, 107, 109, 114, 122, 130, 138, 143, 151, 175, 183, 184, 188]. Manager interest in research [113, 117]. Providing staff training and opportunities for knowledge development as part of the research process [107, 122, 130, 151, 181]. Manager support of the research study [108, 133, 138, 150, 183, 192]. Positive use of spaces that were chosen by residents, for example

Barriers	Facilitators
A lack of private space and disruption of daily routines caused by research [123, 124, 133, 143, 150, 155, 163, 166, 169, 192].	residents' own bedrooms, to conduct research [70, 120, 135, 150, 155]. The culture of care homes, specifically care homes with a culture of inclusiveness [136].

Table 2.5 Advice and recommendations taken from included articles for modifying barriers to research

Issues	Proposed solutions
Research Design	Work with stakeholder organisations when designing studies e.g., CQC, local authorities – consider the perspectives of each individual shareholder but also take into account the relationships and hierarchy both within a care home and between it and other organisations and health professionals. Embed public involvement throughout and consider how to support their involvement through taking account of residents' needs due to cognitive impairment and physical frailty. Allow care home staff to play a key role in identifying eligible residents, share information and introduce researchers to residents. Consider how the consent arrangements will impact on the study – for example ensuring that residents who lack capacity to consent can participate through the involvement of a consultee or legal representative. For each step in recruitment, make extensive plans that build in time, including time to be flexible in the face of

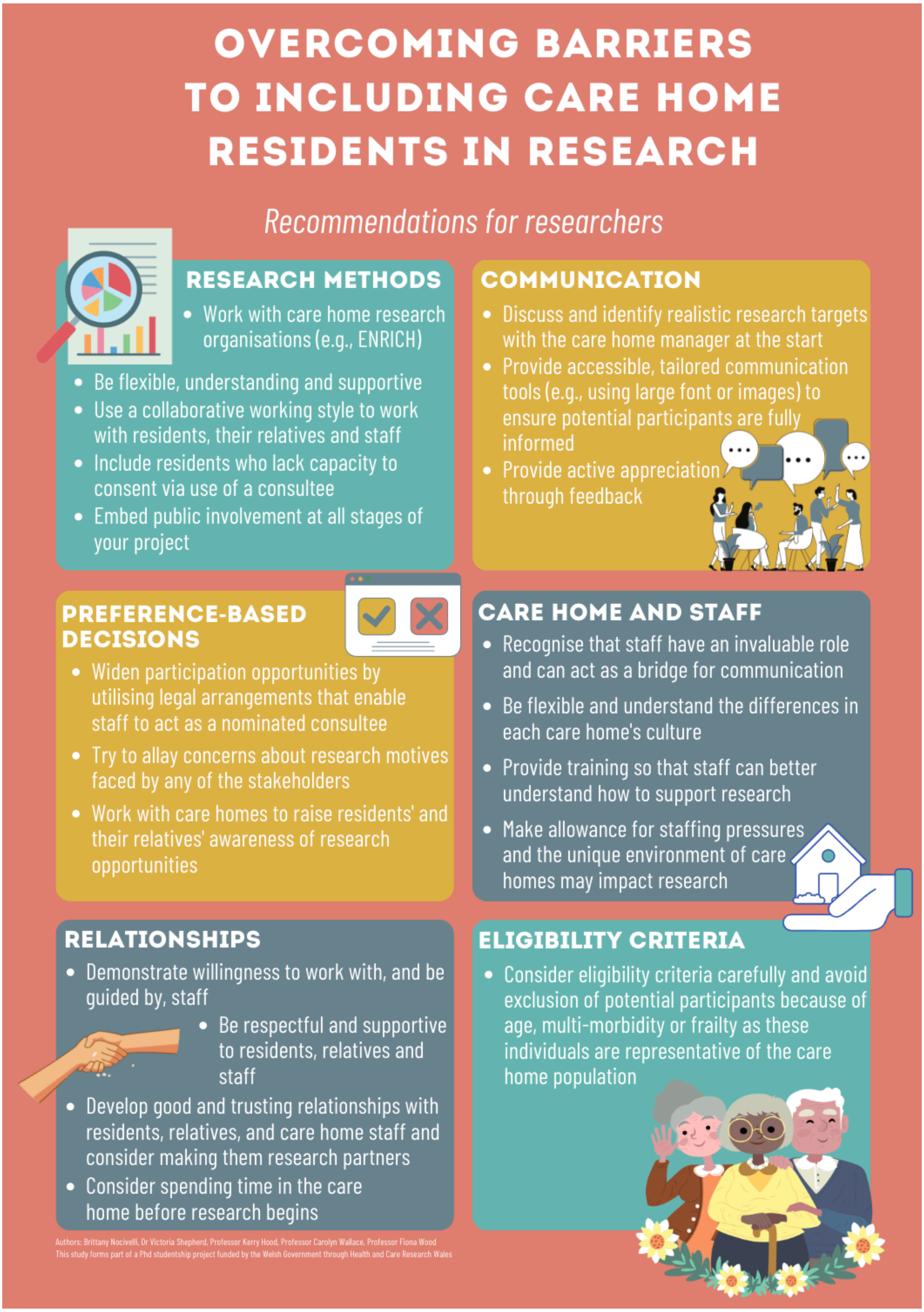
Issues	Proposed solutions
	unexpected hurdles. Adapt measures or questions for participants. Understand that recruitment is a resource intensive process and that it requires a lot of preparatory work. There are many layers of permissions needed to support the recruitment process in care homes. Provide training so that staff can better understand how to support decisions about capacity and communication approaches, and ensure person-centred inclusion research processes. Understand that the staffing pressure and the unique environment of care homes may impact on research – be patient, flexible, supportive and understand the complexities involved, and minimise additional workload for care home staff and any costs associated with taking part. Identify realistic targets with the manager at the start. Take the time to learn about shift patterns and mealtimes – understand that care always comes first, research is not the top priority for staff. Researchers should develop their skills in order to support residents with dementia to participate in research. Be open, responsive, and sensitive – talk to, and work WITH, care home staff.

Issues	**Proposed solutions**
	Provide accessible, tailored communication tools in order to have the best chance of supporting residents to understand the research and provide informed consent.
Communication	Recognise that staff have an invaluable role in supporting residents to understand information about a study and maximise their ability to provide consent if they want to participate. Staff can act as a bridge for communication and advise researchers on any communication aids, best times to approach etc. Ensure that staff have a genuine understanding of the research study, so they share correct information, as well as developing a good relationship with them so that they are happy to help. Consider making them research partners so they feel more included and part of the team. Communicate well with the care home so that staff know when researcher is coming so they can plan ahead – provide opportunities for meetings and be transparent. Identify realistic targets with the manager at the start. Take the time to learn about shift patterns and mealtimes – understand that care always comes first, research is not a top priority for staff. Provide accessible, tailored communication tools in order to have the best chance of getting residents to be fully informed and understand the research – e.g., use of pictorial or print text cards.
Relationships	Care home managers can support with recruitment when explaining studies to residents, the early involvement of residents' families, data collection that takes account of

Issues	Proposed solutions
	residents' needs, tailored information and support for care home staff. Understand the differences in each care home's culture. The influence of the culture within a care home may impact on how care home staff engage with the research, define dementia, and interpret their roles as mediators, protectors and gatekeepers. Develop good and trusting relationships with staff and demonstrate willingness to work with staff – be a respectful researcher and support staff, be guided by managers and staff, try to allay concerns faces by any of the stakeholders, provide active appreciation through feedback.
Eligibility criteria	Avoid intentional and unintentional exclusion of potential participants because of age, multi-morbidity or frailty, or impaired capacity to consent.
Preference-based decisions	Utilise legal arrangements that can be put in place if residents want to participate but have no family to act as a consultee/legal representative e.g., ensuring care home staff can act as a consultee/legal representative. Provide accessible, tailored communication tools in order to have the best chance of getting residents to be fully informed and understand the research.
Care homes	Allow care home staff to play a key role in identifying eligible residents, share information and introduce researchers to residents. Staff can act as a bridge for communication.

Issues	Proposed solutions
	Recognise that staff have an invaluable role in supporting residents to understand information about a study and maximise their ability to provide consent if they want to participate. Staff can advise researchers on any communication aids, best times to approach etc. Care home managers can support with recruitment when explaining studies to residents, the early involvement of residents’ families, data collection that takes account of residents’ needs, tailored information and support for care home staff. Provide training so that staff can better understand how to support decisions about capacity and communication approaches, and person-centred inclusion research processes. Become a ‘research ready’ care home.

Figure 2.2 Infographic developed as an output including recommendations for researchers.



OVERCOMING BARRIERS TO INCLUDING CARE HOME RESIDENTS IN RESEARCH

Recommendations for researchers

RESEARCH METHODS

- Work with care home research organisations (e.g., ENRICH)
- Be flexible, understanding and supportive
- Use a collaborative working style to work with residents, their relatives and staff
- Include residents who lack capacity to consent via use of a consultee
- Embed public involvement at all stages of your project

COMMUNICATION

- Discuss and identify realistic research targets with the care home manager at the start
- Provide accessible, tailored communication tools (e.g., using large font or images) to ensure potential participants are fully informed
- Provide active appreciation through feedback

PREFERENCE-BASED DECISIONS

- Widen participation opportunities by utilising legal arrangements that enable staff to act as a nominated consultee
- Try to allay concerns about research motives faced by any of the stakeholders
- Work with care homes to raise residents' and their relatives' awareness of research opportunities

CARE HOME AND STAFF

- Recognise that staff have an invaluable role and can act as a bridge for communication
- Be flexible and understand the differences in each care home's culture
- Provide training so that staff can better understand how to support research
- Make allowance for staffing pressures and the unique environment of care homes may impact research

RELATIONSHIPS

- Demonstrate willingness to work with, and be guided by, staff
- Be respectful and supportive to residents, relatives and staff
- Develop good and trusting relationships with residents, relatives, and care home staff and consider making them research partners
- Consider spending time in the care home before research begins

ELIGIBILITY CRITERIA

- Consider eligibility criteria carefully and avoid exclusion of potential participants because of age, multi-morbidity or frailty as these individuals are representative of the care home population

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2.4.4 Consultation stage

When presenting the early synthesis to the group of PPI partners, comments were received about choice of vocabulary, much of which reflected terms used by the authors of the literature included in the review. For example, the use of the word ‘overprotective’ in relation to relatives was disliked by one member, stating that it felt harsh and unfair.

Suggestions of additional visualisations of the results were made, such as the inclusion of a graphic showing the weighting of barriers and facilitators depending on how many times each came up in the included literature. The inclusion of a table stating which barriers could be tackled most easily compared to those more difficult to tackle was discussed also.

Further discussion related to one member’s own experiences of working in different types of care homes. For example, for researchers to consider that care home staff may have different time and workload demands dependent upon whether they are working in a residential or nursing home.

Overall, the discussion supported the preliminary findings, including the importance of care home staff to engaging care home residents in research. One member shared their own experiences of visiting a relative living in a care home and the apparent issues of recruitment and pressures of high workload. This member also shared the view that staff often do not have English as a first language, making them more cautious towards research, and that it may be a lower priority for them as it contributes towards their already high workload. The facilitatory benefits of researchers spending time in care homes prior to study commencement was discussed and strongly agreed with by the group members. A suggestion for future research surrounding the topic of how to facilitate conversation between researchers and care home staff about research and its benefits was made by one member.

Changes made in light of the consultation stage included:

- Clarification of the definition of ‘care homes’ as homes which care is provided for older adults and not other types of care homes which might provide care for younger adults with disabilities
- Including a graphic showing the weighting of barriers and facilitators relating to how often they were mentioned in the included literature
- Adding more information to clarify that terms which may be less favourable, such as ‘overprotective’, have been used as these were terms used in the literature
- Including the suggestion of exploring the topic of how to facilitate conversation between researchers and care home staff in future research

2.5 Discussion

The aim of this thesis chapter was to understand why older adults living in UK care homes are often excluded, and therefore underrepresented, in care home research. To achieve this, I aimed to identify resident-related barriers and facilitators to residents’ inclusion and identify potential interventions to appropriately modify identified barriers and facilitators. The barriers and facilitators identified in the existing literature have been collated, synthesised, and reported in this thesis chapter.

The majority of included articles were research articles conducted in care home facilities, although there were also a number of commentary articles from researchers about the processes of conducting research in care homes. Frequently reported barriers and facilitators to the inclusion of care home residents in research were grouped into seven thematic categories: (1) research design; (2) understanding and beliefs about research (resident and care home staff); (3) communication; (4) relationships; (5) eligibility criteria (resident and care home); (6) preference-based decisions; and (7) care home staff and environment. Approaches or solutions suggested in the light of these findings are presented in Table 2.5.

2.5.1 Barriers

Barriers to the inclusion of care home residents in research were mainly related to factors outside of the residents' control (indirect factors), such as research methods and the communication and relationships between research systems and care systems. Strict eligibility criteria for participation, both for residents and for care homes, were identified in a large number of the included articles. Whilst necessary for any study to provide eligibility criteria in order to focus their population of interest, strict criteria relating to characteristics of care home residents, such as age, prevents the inclusion of residents that could otherwise provide a representative sample of the targeted population. This finding supports reporting of other research including older adults, such as within clinical trials of Alzheimer's disease, in which older patients are still underrepresented despite the fact that those aged 80 and over form the majority of patients with Alzheimer's disease [193]. Additionally, an umbrella review exploring whether older adults are insufficiently included in clinical trials also reported that the most frequent missing inclusion of older adults was the use of age limit as exclusion criterion and that more extensive inclusion would require more explicit inclusion criteria [194]. The potential impact of excluding representative participants based on characteristics which may be unrelated to the research aim, or interfere with the research findings, may be unfavourable in relating findings to practice. This is in line with points made by Patino and Ferreira [195] regarding the impact of inclusion and exclusion criteria on the external validity of a study.

Further, there is an apparent possibility of exclusion at a higher level, before opportunities to take part in relevant research studies even reach care home residents, which may be an indirect barrier to their inclusion and also undermine their autonomy. International findings lend support to this, with studies from the United States of America reporting that challenges in recruiting from care homes include owners refusing research to be conducted in their facilities [196, 197] and the impact of changes in ownership [198]. A deterministic approach [199, 200] may be able to explain this and thus the resulting lack of underrepresentation of care home residents in research, whereby this outcome is a result of previous actions of those at a higher level or respective system (e.g., care home owners, senior managers, or relatives), rather than a direct result of a resident’s capacity to make decisions or their ‘free will’. With this view in mind, it might be possible that making efforts to identify predictable barriers early may help inform the development of interventions which aim to improve residents’ autonomy.

The lack of an opportunity for a relative or personal consultee to consent on behalf of a resident who lacks capacity to consent to their own research participation presented a barrier to inclusion in a number of articles included in this thesis chapter. It is likely that including extra steps in research design and recruitment stages, to obtain informed consent from those lacking capacity, can be both time-consuming for researchers and present additional costs, challenges that are consistent with international study findings such as those from Australia [201]. This finding is in line with research suggestions that care home research can be challenging to conduct due to practical difficulties and ethical concerns [202]. Ongoing work aiming to make it easier for researchers to make sure they have appropriately considered how they can include people with impaired capacity is of huge benefit in tackling issues around inclusion in research for underrepresented ‘vulnerable’ populations [203]. Such work has been undertaken, and is ongoing, in other areas of research inclusion with underrepresented populations such as ethnic minorities too [204], highlighting the importance of including populations that better reflect those who may be able to benefit from research.

Other practical difficulties and ethical concerns were identified in this thesis chapter relating to the impact of external factors such as legal frameworks and research ethics committees. Examples of legal frameworks relevant, and influential to, the care home sector include The MCA, 2005 [4], the Health and Social Care Act, 2008 [5], and The Care Act, 2014 [6], all of which are in place to ensure that the rights of individuals, including care home residents, are protected. The findings of this thesis chapter are in line with a recent review of barriers and facilitators by Ritchie et al. [205], which discusses data privacy regulations as a barrier to recruitment causing care home staff to involuntarily act as ‘gatekeepers’. Ritchie and colleagues suggest that by establishing residents’ and representatives’ preparedness to be approached at the point of care home admission, this barrier could be removed.

More barriers than facilitators were identified in this thesis chapter relating to the theme of preference-based decisions. Whilst research generally aims to investigate and discover ways in which we can improve quality of life of a target population, there is a paucity of research aiming to understand how care home residents feel about and understand the purpose and benefits of research, thus in some cases impacting their willingness to contribute or participate. Empirical research findings have shown misunderstandings and misconceptions about elements of research participation, such as informed consent, in the general public [206, 207]. Additionally, clinical research exploring the views of potential participants toward proposed regulations for clinical research with adults unable to consent have suggested a general attitude of distrust and misinformation around research protections (such as ethics committees) [208]. Lending further support to this finding is international literature from the USA and Norway [207, 209]Such findings lend further support to, and can help explain the findings of, the scoping review reported in this thesis chapter.

Expressions of disempowerment by residents, where they questioned their abilities to contribute in a useful way to research, was apparent in the included articles alongside apparent lack of autonomy, confidence, apathy and worries about research participation. This finding is consistent with international literature from France where researchers report residents sharing that they are “too old for this”, “afraid” of taking part, or that they “don’t want to be a guinea pig” [210]. Previous empirical research that has investigated care home residents’ care and quality of life has repeatedly reported how settings, which can be described as institutionalised, have the potential to undermine autonomy and dignity, and with that have discussed disempowerment in care homes. For example, Higgs and Gilleard [211] describe the role the care home environment can play in reducing residents’ perceived identity and autonomy and thus leading to a sense of disempowerment. Further, the role of autonomy in quality of life for care home residents has been explored and has argued that limited decision-making power over routines, activities, and decisions about health care led to feelings of disempowerment [212]. Similar findings have been identified in international literature investigating institutional care for older people in developing countries, such as Argentina [213]. According to Self Determination Theory (SDT) [214, 215], perceived autonomy can result in feelings of empowerment and improve motivation to carry out tasks which are felt to be a product of one’s own choice. Improving perceived autonomy of older adults living in care homes could be beneficial in this research area. Informing and educating older adults living in care homes about research, and how they can be involved, may be a useful step towards increasing opportunities for inclusion.

2.5.2 Facilitators

Not surprisingly, the review reported in this thesis chapter has identified that a number of facilitators to care home resident inclusion in research correspond to identified barriers. For example, poor communication between researchers and residents, relatives and care home staff resulted in more barriers, whereas clear, consistent, and positive communication between individuals and organisations were a facilitator to resident inclusion. Ritchie et al. [205] has also previously identified challenges relating to communication between the research team and care home staff outside of the care home setting, lending support to this finding.

It is apparent, from research exploring the views of relatives, that communication with care home staff is important to them and plays a vital role in their perceived care satisfaction. Davies and Nolan [216] explored relatives’ expectations of care home staff and found that poor communication from staff leads to dissatisfaction with care. The study suggested that staff may focus on clinical care, while relatives prioritise emotional and social aspects of care and that, because of the time demands and differences of priorities of care home staff, these are not always achievable. These findings support some of the barriers identified in the current thesis chapter, and international literature (e.g., [196, 198, 207, 217]), suggesting that differences in priorities and interest, high workload, and time constraints for care home staff, may act as barriers for efficient communication and thus sharing of other opportunities within care home systems. Relatedly, in research exploring preparedness to care for confused older patients, health professionals have suggested that training in tailored communication for staff may help to bridge the gap between residents, staff, and relatives [218]. Similar training could be considered for care home staff in a collaborative effort to share research opportunities.

Furthermore, difficulties in communication experienced by residents, which may pose a barrier to inclusion, may be rectified through the presentation of research information in an accessible and tailored manner by others, thus facilitating inclusion. Influenced by principles of Social Learning Theory (SLT) [219, 220], the Communication Accommodation Theory (CAT) suggests that people make changes in their communication styles to accommodate or match the person they are conversing with [221]. According to the principles of CAT, in order to improve communication within the care home, between residents and other stakeholders, slowing down speech, using simpler words, and utilising repetition where necessary, to match residents' comprehension abilities, are all ways to facilitate the efficiency of communication for care home residents who may have difficulties in understanding information. In a study utilising training based on the principles of CAT, it has been found that care home staff who made adjustments to their communication style to match residents' abilities were more successful in interactions and sharing important information [222]. In addition, the use of non-verbal communication such as visual aids have been shown to be useful for residents with communication difficulties [222]. The principles of CAT, and the research discussed, lend support to the suggestion that a focus on improving communication between stakeholders has the potential to facilitate the inclusion of care home residents in research, ensuring that opportunities are effectively shared and that residents have appropriately tailored opportunities to understand opportunities available to them and share their wishes and preferences.

Within the theme of relationships, a number of other facilitators were identified. The use of a collaborative working style between all stakeholders was discussed as beneficial in a number of articles as were the benefits of developing positive relationships with gatekeepers, such as care home managers. These findings align with reports of beneficial research outcomes of collaborative working styles in other health care settings [223]. The theory of Collaborative Advantage, proposed by Huxham and Vangen [224], highlights the benefits of working together versus working independently. Working collaboratively within complex environments with multiple stakeholders, such as care homes, may have the potential to improve quality of care, as well as intended outcomes. For example, working collaboratively and improving relationships between residents, care home staff, relatives, and external stakeholders, such as researchers, may help to facilitate the inclusion of care home residents in research and overcome a number of identified barriers to their inclusion. Establishing and maintaining these positive, collaborative relationships are of huge importance when considering the shared goal of improving care home practices through the development and application of research-informed, evidence-based strategies. Research applications of the principles of the theory of collaborative advantage have been influential in suggesting that this theory can optimize relationships between stakeholders in care home settings. These research studies include those discussing the establishment of shared goals [225], sustained relationships between care homes and researchers [226], and the management of power dynamics, mutual respect, and equal participation [227].

Within the care home staff and environment theme, capitalising on the unique care home environment such as private rooms and communal social spaces, can facilitate resident inclusion, as shown in some of the included articles. In addition, the high workload and time pressures faced by staff, identified in the included articles, may be addressed by manager support of the research study [117, 133, 138, 150, 183, 192], making researchers aware of the most suitable times to carry out research related tasks. Investing in staff development through training may facilitate positive staff engagement in research, which was identified as a facilitator to the inclusion of care home residents in research. This finding is in line with Gordon et al. [228], who suggest that investing in the development of the care home workforce can help to make staff feel more valued and give them the recognition they deserve to match the importance of their work. There have been a number of other studies that have found that providing care home staff with training opportunities can improve their sense of value and enhance their confidence. For example, training has been suggested to have a positive impact on self-efficacy and motivation [229], and feelings of organisational support [230].

Further, by removing additional research pressures, including time and workload demands, care home staff may be more willing to facilitate resident recruitment. This flexibility relates to suggestions from other included articles in this thesis chapter which state that patience, flexibility, and need for understanding the complexities of care home environments are key researcher qualities needed for successful recruitment and data collection. Research has found that flexibility in research approaches encourages participation by care homes [136, 231], especially when researchers are sensitive to the challenges faced by care home staff in the care home setting and show respect for the pressures care homes face. Research sharing the importance of collaborative and tailored research design [227], as discussed above, also suggests that care homes are more likely to get involved in research when researchers are willing to co-design studies that align with the specific needs, interests, and priorities of the care home. Accommodating staff availability, simplifying processes, and considering the care home's needs, are elements identified as being key in facilitating and encouraging care home participation in research [227].

2.5.3 Identified gaps in the literature

Apparent from the findings of this scoping review is the lack of research investigating ways in which researchers can improve the inclusion of care home residents in research. More research is needed to understand why care home residents are so often excluded from taking part in research, the impact of this exclusion on representation, and how we can facilitate inclusion.

2.5.4 Strengths and limitations

In accordance with scoping review methodology, an assessment of the methodological quality of included articles was not undertaken. However, the aim of this review was to identify underlying concepts in the research area, as well as key sources and the nature of available literature [104], for which a scoping review was the most appropriate approach [98]. Whilst a large amount of literature was identified, a number of common themes were identified which allows confidence in application of the broad yet rigorous scoping review methodology. Further, another strength arises from the inclusion of a broad range of article types, such as blogs and other non-academic literature, given that many of the barriers and facilitators are reported in sources other than peer-reviewed journals. However, these additional sources may not have undergone external peer-review. Although a comprehensive search was carried out, with a focused but inclusive search strategy, it is possible that all published articles in this area were not identified.

A strength of this review is the inclusion of both direct and indirect barriers and facilitators which were identified during data extraction and are thought to have a great impact on older adults' inclusion in research. Other strengths include that data were included from a wide range of study types and stakeholders' experiences, enabling the findings to be drawn from these wider perspectives rather than those of individuals studies or groups. A further strength of this scoping review was the inclusion of the consultation stage of Arksey and O'Malley's methodology framework, often omitted by researchers, which allowed the exploration and clarifying of our preliminary findings using additional expertise and perspectives of stakeholders.

2.5.5 Future research and practical implications

This thesis chapter provides new insights into the barriers and facilitators to care home residents' research participation presented in the existing literature. Many of the barriers have the potential to be modified, thus improving recruitment and inclusion. It may be of interest for future research to investigate barriers and facilitators for different types of care home or for residents with differing characteristics (e.g., those with capacity to consent and those without). Furthermore, future research may also consider the different barriers to the inclusion of care home residents in research depending on the type of research methodology (e.g., randomised controlled trials vs survey studies). It was apparent that strict eligibility criteria presented a barrier in a large amount of include articles, regardless of intervention type, and other barriers such as reported research burden were apparent in interventions implemented over a period of time rather than at one time point. Future research work identifying the specific differences in barriers and facilitators to resident inclusion between different research methods and intervention types may be useful in providing further insight into such factors and inform future development of interventions targeting barriers to the inclusion of care home residents in research.

Apparent from the findings of this thesis chapter was a lack of literature reporting the views of relevant stakeholders (i.e., residents, relatives, staff, and researchers) about the opportunities for older adults living in care homes to get involved in research. Future research may also consider focusing on the development of a simpler process of involving people without capacity to consent in research, with a specific focus on care home residents. This would need to include individuals living with dementia who represent the majority of older adults living in care homes. Furthermore, future research to explore how residents' wishes and preferences about research participation, and the quality of understanding about research by this population may be useful in improving recruitment practice.

Finally, attempts to address the identified barriers to resident inclusion can be made using the solutions identified in this review. Tools have recently been developed which aim to help researchers to design trials that are more inclusive of particular underserved populations (e.g., the INCLUDE Ethnicity Framework [204], and the INCLUDE Impaired Capacity to Consent Framework [203]) but have not yet been applied to trials being conducted in care homes. If these are successful, researchers may expect their results to be more generalisable to this underrepresented population who may benefit the most.

Findings around challenges in communication were of particular interest and informed the work following this thesis chapter. Such challenges relating to communication are complex, identified both within and between system levels, and all have the potential to influence resident inclusion in research. Additionally, the survey and interviews conducted in the next stages of this thesis provided opportunities to gain important new insights into how these challenges are experienced by stakeholders.

2.6 Summary

Care home residents remain an under-served group in research, which results in less evidence about how to best care for this group than those receiving care in other settings. Through the use of scoping review methodology, this thesis chapter identified a number of complex, interacting barriers and facilitators to the inclusion of older adults living in UK care homes in research. The findings have enabled a better understanding of common barriers and facilitators to the inclusion of care home residents in research, as well as presenting potential ways these factors can be modified to improve research within the field.

2.7 Reflections

The overall process of planning, conducting, and reporting this thesis chapter was enjoyable, and I enjoyed the systematic element of the methodological framework that was followed.

Whilst I originally set out to only identify resident-related barriers and facilitators to the inclusion of care home residents in research, it was quickly realised that doing so would over-simplify the complex interaction between a number of factors and systems which influenced care home residents' inclusion in research. Because of this I soon decided that I would include factors at all system levels and try to describe their influences, both direct and indirect, on the inclusion of care home residents in research.

Chapter 3 - A survey exploring stakeholders’ views about opportunities for older adults living in UK care homes to participate in research

3.1 Chapter overview

This chapter reports a survey study undertaken as part of this thesis. A version of this chapter has been published as an article: Nocivelli, B., Wood, F., Hood, K., Wallace, C., & Shepherd, V. (2024). Widening research participation: a survey exploring stakeholders' views about opportunities for older adults living in UK care homes to participate in research. *Nursing And Residential Care*, *26*(7), 1-9.

This chapter contributes to the objectives of this thesis by further investigating the barriers and facilitators to the inclusion of care home residents in research and views about opportunities for older adults living in care homes to participate in research. Additionally, this chapter provides insights into stakeholders’ beliefs about the greatest barriers to care home resident inclusion in research and how these could be addressed. Implications for future research are also discussed.

3.2 Introduction

The barriers and facilitators to the inclusion of UK care home residents in research have been investigated through the scoping review presented in Chapter 2 and published [58]. Complex factors were identified, including research design; understanding and beliefs about research; communication; relationships; eligibility criteria; preference-based decisions; and care home staff and environment. These findings were able to lend support and validate findings of previous research to identify challenges of conducting research in long-term care facilities across a number of geographical locations [52]. Importantly, the review found a lack of research exploring the views and experiences of relevant stakeholders (i.e., care home residents, relatives, care home staff) about the opportunities for older adults living in care homes to get involved in research and the barriers they believe residents face. The findings of Chapter 2 largely informed this stage of the project. With PPI, the findings of the scoping review were used to develop the design and content of the survey, with questions focusing on participants' views about current research opportunities for residents to take part, what helps or prevents residents being included in research, and how to support residents to make decisions about taking part in research."

3.2.1 Chapter aims and objectives

The aim of this chapter is to explore the views of care home residents, relatives, care home staff, other Health and Social Care Professionals (HSCPs) who work with care homes, and researchers about current opportunities for residents to participate in research, decisions about participation, and the barriers and facilitators to their involvement.

3.3 Methods

3.3.1 Design

Cross-sectional studies have been described as observational studies that analyse data from a population at a single point in time, useful for establishing preliminary evidence in planning a future more complex study [232]. In a cross-sectional study, researchers are able to gather data on a number of variables simultaneously, which allows them to analyse associations between variables but not causal relationships [233].

A cross-sectional survey was developed for this study and was available in an online- or paper-based format, depending on the preference of the participant. Conventional content analysis was conducted on the text-based data collected through the survey in order to gain insight into, and interpret, views shared by stakeholders in response to purposefully designed survey questions and answer options.

Content analysis is a research method that can be used to systematically analyse the content of text data (as well as other data formats). This approach to data interpretation can be applied in both quantitative and qualitative research to support researchers to identify insights into how information is represented and interpreted [234].

3.3.2 Participants and recruitment

Participants comprised of relevant stakeholders who were in the position to have potentially had experience of research in care homes. This included care home residents, relatives of care home residents, care home staff, other HSCPs who work with care homes, and researchers.

Due to the objectives and design of this exploratory study, conducting a formal sample size calculation was not deemed relevant. A target size of around 100 participants was estimated from similar studies (e.g., [235]). My intention was to include a diverse range of stakeholder perspectives with the aim of maximum variation with available resources [236].Participants were provided with detailed information about the study and consented to taking part.

Participants were identified and recruited through a number of different routes which were chosen as they were the most likely way to reach one of the stakeholder groups. The contact information for care homes within an appropriate travelling distance was accessed through council websites and other online searches, and both direct and indirect contact was made through emails and telephone calls to individual care homes. Opportunities to recruit stakeholders at relevant academic conferences were taken through the inclusion of recruitment advertisements in the form of QR codes on both poster and oral presentations. Recruitment adverts were shared with members of existing established networks including ENRICH (England, Cymru, and Scotland) and the British Society of Gerontology Special Interest Group (BSG SIG). Further, researchers of ongoing care home studies were identified through the NIHR and contacted via email with a link to the online survey and General Practitioners (GPs) were recruited through the PRIME Centre Wales research centre. Social media, including Twitter/X and Facebook, was used to share the recruitment advert more widely. This included a link to the online survey. Incentives for participation were not offered at this stage of the project.

3.3.3 Questionnaire design

The findings of the scoping review (Chapter 2) largely informed the development of the survey, ensuring that the questions were focused and influenced by both published empirical literature and relevant grey literature.

The survey included both fixed-choice and ranking questions with free-text boxes throughout for participants to include any additional information they deemed relevant. Fixed-choice answers were designed to explore stakeholders' views about identified barriers and facilitators to the inclusion of care home residents in research, as well as recommendations to overcome challenges. Ranking questions were designed to gain an understanding of stakeholders' opinions about the greatest and least relevant barriers and facilitators to care home residents' research inclusion. By understanding what is most important and relevant to stakeholders, suggestions could be developed about which target areas may be most beneficial to prioritise in future research.

The survey was divided into four sections: (1) demographic data ('About You'); (2) views about current opportunities for residents to take part in research; (3) views about what helps or prevents residents being included in research; (4) views about how to support decisions about taking part in research. Participants were also given the option of providing contact details if willing to be contacted about taking part in an interview for the next stage of the study. The survey can be found in Appendix 3.1.

3.3.3.1 Patient and Public Involvement (PPI)

Alongside the development and completion of the scoping review detailed in the previous chapter of this thesis, the ENGAGE study recruited a PPI group who assisted in the development and refinement of the survey content. At this stage of the project, the PPI group comprised of a relative, a member of care home staff, and a relative who also has experience as a researcher.

The first virtual meeting of the ENGAGE study PPI group was held on 28/06/2022 led by the researcher and supported by a supervisor. Draft documents, including the participant information sheet, survey recruitment advert, and the actual survey, were sent to PPI members a week prior to the meeting with instructions to read them in preparation for the meeting, and consider the following questions:

- Is the information clear and easy to understand?
- Is the language used appropriate for care home residents, staff, relatives, HSCPs, and researchers?
- Do you have any suggestions about how to make the information more accessible?

A presentation was then shared detailing the project background, the research and its progress so far, and survey development. PPI discussion and relevant changes to the survey document content are detailed in Table 3.1.

Table 3.1 Resulting changes to the survey design and content following PPI consultation

Survey section	**PPI group comments/suggestions**	**Changes made as a result**
General	Suggestion to change *“all”* to *“any”* in the instructions following each question: *“Please tick any that apply.”*	Change made throughout.
Section 1 – About You	Members were happy that the questions in this section were clear and appropriate for the	

Survey section	**PPI group comments/suggestions**	**Changes made as a result**
	targeted population of this study.	
Section 2 – Your views about current opportunities for residents to take part in research	PPI group members suggested that potential participants may not know how to answer the stand-alone questions and that they may benefit from prompts to ensure their answers are useful and focused.	Following discussion, a list of potential answers for each question were included, informed by our scoping review findings, and stated that participants should tick any that they believed applied to answer the question. A 'other' option was also listed as an answer with a free-text section so that participants had the opportunity to share additional information they believed to be relevant to the question.
Section 3 – Your views about what helps or prevents residents being included in research	Suggestions that additional information is given about how participants were expected to answer the ranking questions. Suggestion to expand on some of the phrasing and	Further instructions were given for the ranking task. For example: the inclusion of *"(1 being the greatest factor and 5 being the least)".* More accessible language was used. For example:

Survey section	**PPI group comments/suggestions**	**Changes made as a result**
	language used in the statements to be ranked in this section to ensure clarity for participants.	*"Tailored communication"* was changed to *"Changing communication style depending on participant needs".* *"Strict inclusion and exclusion criteria"* was changed to *"Requirements for participation being too strict".*
Section 4 – Your views about how to support decisions about taking part in research	The phrasing of some of the included answers for participants to choose from was discussed and suggestions were made to make the language more accessible for potential participants.	The phrasing of relevant statements was modified. For example: *"Ensure decision-making is a multi-staged process to accommodate varying degrees of cognitive awareness and mental capacity among potential participants"* was changed to *"Provide a personalised decision-making process to the needs of each potential participant".*

3.3.4 Data collection

The survey was developed and conducted using an online survey tool (Qualtrics) and an alternative paper version of the survey was available. Participants were invited to complete the survey online through a link, or a researcher was available to go into the care home to support residents to complete the survey either on paper or via an iPad if required.

A small pilot was conducted with a group who fulfilled the inclusion criteria (*n*=3; two researchers, and a relative of a care home resident) to test the survey acceptability, comprehensibility, and content. Minor amendments to the survey design and content were made following the pilot including improving the usability of the online version.

The survey launched on 27th September 2022, following the pilot, and closed on 9th December 2022.

3.3.5 Data analysis

Paper-based survey responses were entered into the online survey to support data management and analysis. All survey data were exported from the online survey tool. Data cleaning was conducted, removing respondents that only minimally engaged (e.g., started the survey but did not answer any questions); or those that did not complete the statement indicating consent.

A conventional content analysis was performed on free-text responses to individual questions and common themes were identified. This was achieved through firstly defining categories, coding the content, analysis, and interpretation, as is typical for content analysis [237], and responses were coded in Microsoft Excel.

A weighted scoring method was used, where factors were given a higher value or ‘weight’, to analyse responses to questions which involved ranking factors based on previous literature (both questions in Part 4). Answers ranked in first and second places were weighted and totalled to calculate what stakeholders deemed the greatest barrier/enabler (first place x10, second place x5). Answers ranked in fourth and fifth places were weighted and totalled to calculate what stakeholders deemed the least important barrier/enabler (fifth place x10, fourth place x5).

3.3.6 Ethical considerations

Prior to survey commencement, ethical review was carried out by Cardiff University School of Medicine Ethics Committee and favourable opinion was obtained (SMREC reference: 22/50; see Appendix 3.2). Participants were provided with an information sheet about the study (see Appendix 3.3), which included information about the research purpose, data storage, and contact details for more information if required prior to participation. As the study was conducted using an online survey tool a separate consent form was not required for those completing the survey using this format [238], however participants were required to agree with a statement confirming that, by completing the questionnaire, they were consenting to take part in the study. Those participants who chose to complete the survey in-person, using a paper version, were required to ‘tick’ a box confirming that they were consenting to taking part.

3.4 Results

3.4.1 Participants

A total of 80 responses to the survey were recorded (74 online and 6 paper). However, responses were excluded from analysis if they: provided minimal or no demographic data (n=18); or started the survey but did not answer any questions (n=16). A total of 46 responses were included in analysis (see Table 3.2 For demographic characteristics of participants). Stakeholders included care home residents (13%), relative/friend of care home residents (24%), care home staff

(31%), other HSCPs who works with care homes (15%), and researchers (17%). Care home staff and other HSCPs who work with care homes were able to provide details about their role within a free-text box. Responses from care home staff (13/14) included: care assistant (n=2), administrator (n=1), trainee advanced clinical practitioner (n=1), head of dementia care (n=1), home manager (n=6), assistant manager (n=1), and responsible individual (n=1). Responses from HSCPs (6/7) included: social worker (n=2), registered nurse (n=1), GP (n=1), clinical quality nurse (n=1), and clinical studies officer (n=1).

The average length of experience either working with or living in a care home was 92 months but length of experience ranged greatly (from 1 to 564 months).

Table 3.2 Demographic characteristics of participants (n = 46)

	No. (%)
Stakeholder	
Care home resident	6 (13)
Relative/friend of resident	11 (24)
Care home staff	14 (31)
Other HSCP who works with care homes	7 (15)
Researcher	8 (17)
Location of care home	
Wales	20 (44)
England	24 (52)
Scotland	2 (4)
Northern Ireland	0 (0)
Length (duration) of experience, mean (range), months	
Living in/working with care homes	92 (1-564)
Age	
18-35	6 (13)
36-55	20 (44)
56-75	16 (35)
76-95	3 (7)
Missing data	1 (2)

3.4.2 Survey responses

Sharing research opportunities with residents and their families

Participants were asked how opportunities to take part in research were currently shared with care home residents and their families. ‘Care home staff’ was the most chosen answer, followed closely by ‘posters or information sheets’. The answer least chosen was ‘social media’. All responses can be seen in Table 3.3.

Free-text responses to this question (*n*=16) related to issues such as lack of opportunities and methods of sharing. Responses from residents and relatives highlighted a lack of research opportunities. For example, one care home resident shared that *“they’re not”* when asked about how opportunities to take part in research were currently shared with them, and one relative’s response was that they had *“never been approached”.* Answers relating to the methods of sharing research opportunities, were reported by either care home managers, researchers, or HSCP, not by residents or relatives, and related to ways in which research is shared with residents and relatives. For example, one researcher stated that *“Clinical studies officers visit their local ‘research ready’ care homes to discuss opportunities”.*

Making decisions about resident participation

Participants were asked how they believed decisions about residents taking part in research are usually made. The most frequently chosen answer was ‘resident makes own decision’, with proxy/personal consultee or representative make decisions the answer least chosen. All responses can be seen in Table 3.3.

Free-text responses to this question (*n*=8) related to issues such as a lack of knowledge, and that care home staff controlled residents’ access to research. Some relatives and HSCP reported a lack of knowledge about how decisions about research participation are made. One relative reported *“never [having] received a request”,* and a HSCP expressed their lack of knowledge, stating *“I don’t know”.*

Further, comments relating to the perceived control of care home staff came solely from researchers, one example being *“Care home staff may control access (gatekeeper role)”.* Other responses included reference to residents’ capacity to make decisions about participation, which was discussed by a member of care home staff, and opportunities from outside networks which were mentioned by a HSCP.

Improving opportunities to take part in research

Participants were asked how opportunities to take part in research could be improved for residents. All answers were popular (chosen between 21 and 36 times), with the most selected answer ‘researchers visit care homes and share opportunities’. The least selected option was ‘care home staff share opportunities regularly’. All responses can be seen in Table 3.3.

All free-text responses to this question (n=7) related to issues surrounding optimal use of resources as a way of improving opportunities for participation, reported by all stakeholder groups, except for relatives. One resident reported that it is *“Better if someone comes in”,* for example. Other responses included the role of research ethics committees in *“allowing”* residents with dementia to participate in research.

Barriers to resident research participation

Participants were asked to rank statements in order of which they considered the greatest barrier to residents taking part in research.

The statement that was considered the most impactful barrier to residents taking part in research was lack of awareness about research opportunities (n=29), followed by difficulties with residents’ communication needs (n=18). The statement ranked as the least impactful barrier to residents taking part in research was residents’ feelings of not being heard or valued (n=28), followed by understanding or attitudes about research (n=13).

Enabling resident research participation

Participants were asked to rank statements in order of which they considered most enabling for residents to take part in research.

The statement that was considered the most impactful enabler to residents taking part in research was positive staff engagement (n=23), followed by flexibility of researchers within the care home around organisation and routines (n=15). The statement ranked as the least impactful enabler to residents taking part in research was being part of a care home that has previously been involved in research and is registered as ‘research ready’ (n=23). This was followed by flexibility of researchers within the care home around organisation and routines and better understanding and positive attitudes about research (n=15).

Communicating information about research to residents and families

Participants were asked how information about research could be better communicated to residents and their families to help decide about participating in research. The most selected answer to this question was ‘developing relationships between researchers, care home residents, family members and staff’ and the least chosen was ‘provide a personalised decision-making process to the needs of each potential participant’. All responses can be seen in Table 3.3.

Free-text responses to this question (*n*=5) related to issues such as recruitment and research methods, and communication and relationships. A suggestion on how to improve communication by researchers was shared by one member of care home staff, suggesting that “more publicity” may help. Responses related to communication and relationships were made by care home residents, staff and researchers and surrounded researcher flexibility and accommodating individual participant needs. For example, *“Explain what you’re doing”* was expressed by one resident supported by a response by a member of care home staff, stating that *“Residents are generally willing participants in voicing views. The format, communication and simplicity is required to encourage them to complete in their own time”.*

Supporting residents to express their views about taking part in research

Participants were asked to select how they believed residents could be supported to express their views about taking part in research in the future, should they not be able to make their own decisions about taking part at that time. The most selected answer was ‘Talking to residents about what their preferences would be about taking part in future research’ followed closely by ‘Using tools such as communication aids (e.g., picture cards) to help residents express their views’. All responses can be seen in Table 3.3.

Free-text responses to this question (*n*=9) related to barriers to resident research participation such as resident disinterest; method of consent; inclusion; and support not being possible. Residents reported a lack of interest in expressing their views about taking part in future research, for example one resident stated they would be *“Happy for family to decide”.* Comments including more practical suggestions, including methods of consent, were made by researchers, and one response from a relative referred to their involvement as a means of support for resident inclusion in research. One response from a care home staff member was cautious of supporting residents to express views on participation stating that *“Very often communication is not possible with residents”.*

Table 3.3 Responses to survey questions

	No. (%)
How are opportunities to take part in research currently shared with residents and their families? (*n* = 45 responses)	
Care home staff	25 (56)
Other HSCPs	13 (29)
Social media	7 (16)
Posters or information sheets	21 (47)
Researchers	12 (27)
Other	17 (16)
How are decisions about residents taking part in research usually made? (*n* = 44 responses)	
Resident makes their own decision	34 (77)

Care home staff make decisions	14 (32)
Family/friends make decision on residents' behalf	19 (43)
Proxy/personal consultee or representative makes decisions	9 (20)
Other	8 (18)
How do you think opportunities to take part in research could be improved for residents? (*n* = 46 responses)	
Researchers visit care homes and share opportunities	36 (78)
Care home staff share opportunities regularly	21 (46)
Multiple formats of sharing opportunities (such as posters, leaflets, talks)	28 (61)
The care home actively seeking to take part in research	22 (48)
Other	7 (15)
How can information about research be better communicated to residents and families to help make a decision about participating in research? (*n* = 41 responses)	
Present information in a way that is personalised and relevant to each resident or family member	25 (61)
Clear, concise format – provide choice of information type	28 (68)
Developing relationships between researchers, care home resident, family members and staff	34 (83)
Staff engagement and support	25 (61)
Care home becoming a 'research ready' care home	21 (51)
Give residents time and encouragement to make decisions	28 (68)
Include family members from the very start	30 (73)
Flexibility and understanding of researchers	24 (59)
Provide a personalised decision-making process to the needs of each potential participant	19 (46)
Other	5 (12)
How can residents be supported to express their views about taking part in research in the future should they not be able to make their own decisions about taking part at that time? (*n* = 41 responses)	
	28 (68)

Talking to residents about what their preferences would be about taking part in future research	24 (59)
Using tools such as communication aids (e.g., picture cards) to help residents express their views	9 (22)
Other	

3.5 Discussion

The majority of stakeholders in this study shared the view that current opportunities for residents to participate in research are primarily shared by care home staff. This highlights the important role care home staff can play in sharing research information and recruiting and supports findings reported in the previous chapter. This finding is supported by similar recommendations as seen in the research literature [175]. However, due to the impact of research on care home staff, including potentially increasing time pressures and workload [148], as well as potential research burden [123], this additional research-advocate role is not something that all care home staff can, or are willing to, engage with. There are a number of suggestions in the literature, relating to facilitating the beneficial role care home staff can play in the recruitment and retention of care home residents in research. One suggestion includes fostering a supportive environment in which staff feel valued and are rewarded for their research participation which can be achieved through providing time, resources, and recognising their contributions through formal acknowledgement or incentives [58]. Similarly, regularly communicating the impact of research to staff could be beneficial in helping to demonstrate the value of their participation and provide a sense of connection between their involvement and tangible benefits [130, 180]. Additionally, providing education and training for care home staff members has been suggested in the literature, both providing a benefit to staff and also potentially improving staff confidence and motivation to participate [58, 239]. The mechanisms through which these suggestions may facilitate the inclusion and participation of care home staff in research are in line with the principles of the cost-benefit theory proposed by Drèze [240] which explains that people make decisions based on maximising benefits whilst minimising costs. In this case, because of the potential burden research can impose on staff who already have a high workload, it is important that they perceive a personal gain from investing their time and effort in research, which may come from monetary incentives, free training, or feeling a sense of value and purpose.

Findings from the present study highlighted contradictions between care home residents’ and relatives’ views about research opportunities in comparison to the professional stakeholders’ views, not identified in studies included in the previous review chapter in this thesis. Whilst care home residents and relatives expressed the view that there is a lack of opportunities shared with residents about taking part in research, other stakeholders reported that research opportunities were regularly shared. This discordance between stakeholders’ views has also been reported in studies including care home residents, for example studies investigating residents’ quality of life in a care home [186]. Other reports of discordance between the views of care home residents, staff, relatives, and policy makers have been identified in the available literature including those relating to perceived autonomy and control [241], wellbeing [242], and communication and relationships [243]. Such studies underscore the importance of ensuring that care home research, and practices, are aligned with the actual needs and perceptions of residents. To bridge these gaps, it is essential that residents are involved in decision-making processes and that continuous feedback is collected from them to ensure an accurate assessment of their well-being and quality of life.

Cognitive dissonance theory [244] can explain differences between perceptions of care home residents and other stakeholders including those related to perceptions of quality of care, well-being, and communication and understanding. For example, potential discomfort in facing differences between expectations and reality. If care home staff or relatives have certain expectations about the quality of life in the care home that are not met by residents’ experiences, cognitive dissonance may lead them to either re-evaluate their expectations or alter their interpretation of the residents’ feedback. They might emphasise the positive aspects of care or blame external factors for any negative feedback to maintain their belief in the adequacy of the care provided and the residents perception of their wellbeing and quality of life [245].

Identified differences in beliefs between stakeholders also suggests a lack of effective communication between stakeholders. This is consistent with the findings of the previous chapter and of other research findings that present communication challenges as a barrier to recruitment in care home research [125, 166, 180]. Poor communication between stakeholders can often contribute to misunderstandings, dissatisfaction, and poorer quality of care and has been attributed to lack of time and resources [166], physical or cognitive impairments that hinder effective communication for residents [192], differences in expectations and understanding [136, 152], hierarchical structures and power dynamics [58], and inadequate feedback mechanisms [130, 180].

Furthermore, differences were apparent between the views of stakeholder groups about how decisions are made about residents taking part in research. Relatives seemed to be less informed about the decision-making process, which is consistent with reports of sub-optimal communication between care home staff, researchers, and relatives [70, 142]. Further, research evidence suggests that relatives frequently report feeling inadequately informed about their loved one's daily life and care which often results in feelings of frustration and dissatisfaction [246]. The impact of apparent communication practices can also lead to relatives feeling excluded and less knowledgeable about their loved one's situation [243].

Most stakeholders reported a lack of awareness about research opportunities and difficulties throughout the survey, with resident communication as the greatest barrier to residents taking part in research. These findings are consistent with research suggesting that residents are unaware of research opportunities and are often overlooked with regards to being suitable for participation [114, 150, 159], as well as a suggestion that an act as simple as directly asking residents if they wish to participate in research may be a facilitator to inclusion [150].

Interestingly, stakeholders viewed residents' feelings of not being heard or valued as the least impactful barrier to resident inclusion in research. Frequent reporting of residents' worries about research participation, perceptions of disempowerment and lack of autonomy in the available literature [118, 135, 136, 143, 186], including that found in the previous chapter, contradict the views reported by stakeholders in this study, suggesting that they are unaware of residents' true feelings. This presents another example of the apparent discordance between stakeholders' views, as discussed above. Perceptions of a lack of autonomy and disinterest were also highlighted in residents' comments about how they could be supported to express their views about future research participation should they no longer be able to make their own decision.

Stakeholders viewed positive staff engagement, and the flexibility of researchers around the organisation and routines in care homes, as the greatest facilitators to resident inclusion in research which is consistent with the previous chapter findings and the wider literature. Fossey et al. [130] suggest that positive staff engagement, including seeing staff as 'part of the research team', were invaluable in both recruitment and delivery of research studies in care homes. Theories of collaborative working, such as Collaborate Problem-Solving theory [247], attest to these suggestions and explain the importance of joint efforts to effectively address problems and make decisions. These findings are further supported by recommendations from experienced care home researchers which include the importance of researcher flexibility in facilitating inclusion [70, 106, 107, 114, 130].

Stakeholders viewed being part of a care home that has previously been involved in research and is registered as 'research ready' as the least impactful facilitator to resident inclusion in research. This may be due to a lack of understanding about what a 'research ready' care home is or the successes of organisations aiming to improve research in care homes, such as ENRICH. ENRICH have made recommendations that education around research would be beneficial for stakeholders to ensure that they are fully informed about what research is and its potential benefits, as well as what participation entails [106]. Having this understanding may improve the interest in, and uptake of, research participation.

3.5.1 Strengths and limitations

This is the first study to explore stakeholders' views on care home resident research participation and provides insight into a wide range of views on research opportunities, decision-making, and the barriers and facilitators to research participation for UK care home residents. A strength is the use of conventional content analysis on free-text responses to allow further expression of views. Knowledge generated from the analysis is based on all stakeholder participants' unique perspectives [237].

The study was limited by the modest sample size and the small number of participants who were care home residents. The recruitment approach meant that the non-responders were not able to be tracked, which may have resulted in participation bias. It is possible that offering incentives for participation may have benefitted recruitment. Difficulties were encountered gaining access to care homes and, because of the small size of this stakeholder group, it is likely that their views captured in this study may not be representative of all care home residents in the UK. It should be noted that resident and relative stakeholder groups may only have been able to provide limited experiences based on a particular care home, which may not be research active, whereas other stakeholder groups may have wider experience across the care home sector. Furthermore, recruiting only care home residents with the capacity to consent to participation limits the generalisability of these findings to residents who may be unable to consent to participate in research.

It is also important to consider the potential limitation of all participants receiving the same survey, rather than versions with text adapted to each stakeholder group. Whilst questions may have been clearer to participants if only addressing the particular stakeholder group to which they belonged, PPI contribution during survey design suggested that it would be acceptable to present the same survey to all participants, given that they were addressed in the question. All participants completing the same version of the survey also facilitated data analysis.

Lastly, and whilst not necessarily a limiting factor, it is important to note the implication of the study's inclusion criteria. The requirement of participants fitting the role of stakeholders who are in the position to have potentially had experience of research in care homes meant that some participants were drawing on hypothetical views rather than actual experiences.

3.5.2 Future research

The findings help to understand what stakeholders deem to be the barriers and facilitators to resident inclusion in care home research and how opportunities for inclusion can be improved. These findings can support the development of strategies to improve communication and relationships between stakeholders, as well as training programmes to educate stakeholders about care home research and its benefits, and targeted interventions to improve research inclusion for UK care home residents.

3.6 Summary

In this cross-sectional survey, a range of stakeholders identified what they believe to be the most important barriers to the inclusion of care home residents in research and suggested ways to address them. Discordance between stakeholders’ views were apparent, particularly between residents and other stakeholders, suggesting that communication between stakeholders is not effective and would benefit from strategies or interventions to improve how opportunities and preferences about research are communicated.

These findings also provide evidence to support the importance of developing strategies to improve communication and relationships between stakeholders, as well as training programmes to educate stakeholders about care home research and its benefits, and targeted interventions to improve research inclusion for UK care home residents.

3.7 Reflections

When planning this study, it was the first time I had developed and completed the process of obtaining ethical approval from an ethics committee. Thanks to my supportive and knowledgeable supervisors, creating the study protocol and other relevant documents to support the ethics application was reasonably challenge-free and enjoyable. Whilst I completed the application documents and submitted weeks before the deadline for review – I realised that the email was stuck in my email outbox. This was an annoying mistake and meant that I had to wait for the next submission deadline to have my application reviewed, pushing back the anticipated start date for the study. However, after meeting the next deadline, the application promptly came back with favourable opinion subject to a few small amendments which were completed quickly, and the recruitment process was able to begin.

Whilst I have previously worked with most of the stakeholders targeted to recruit for this study, including care home residents, staff, relatives, and HSCPs, I did not fully anticipate the challenge I would have in getting a response from care home managers to share the opportunity for residents and staff to take part.

Whilst other stakeholders such as staff, relatives, HSCPs, researchers could be reached through emails, social media, conferences, sharing via networks and other connections, I realised that directly contacting care home residents was not even an option. In order to present a question to residents about whether they would consider taking part I needed to speak to care home managers (which was a huge challenge), receive their permission to come in and visit the care home and its residents, ensure that I was able to visit during an appropriate time for both staff and residents according to their daily schedule, and catch residents when they were receptive to visitors and entertaining a task which would require effort and concentration.

After months of advertising and a final push for recruitment towards the anticipated closing of the survey data collection no more responses were received and so it was decided that the survey would be closed to begin data analysis. I was pleased with the number of responses received to the survey but did not anticipate how many I would have to discard from my analysis due to incompletion etc. After data cleaning I was left with 46 responses to analyse, rather than the initial expected 80, which was slightly disappointing as it was even further from the proposed 100 responses to be collected as stated in the study protocol.

Chapter 4 – A qualitative interview study exploring stakeholders' views about advance planning for care home residents' research participation

4.1 Chapter overview

Chapter 4 presents a qualitative interview study undertaken as part of this doctoral thesis. A version of this chapter has been published as an article in the journal 'Age and Ageing' in October 2024: Nocivelli, B., Wood, F., Hood, K., Wallace, C., & Shepherd, V. (2024). "Research happens a lot in other settings—so why not here?" A qualitative interview study of stakeholders' views about advance planning for care home residents' research participation. *Age and Ageing*, *53*(10), afae235, with an accompanying editorial: Drummond, M., Cartin, K., Shenkin, S. D., & Burton, J. K. (2024). Facilitating equitable research access for people living in care homes. *Age and Ageing*, *53*(10), afae220. An infographic containing recommendations for improving engagement in research has also been developed as an output from the findings of this study (Appendix 4.1).

This chapter contributes to the overall aim of the ENGAGE study by identifying barriers and facilitators to care home residents' participation in research, and exploring stakeholders' views about encouraging early discussions to elicit residents' wishes and preferences about research participation. Further, this chapter provides insight into stakeholders' beliefs around research participation for care home residents and suggestions for successful implementation of a supportive intervention to facilitate these early discussions. The implications for intervention development are also discussed.

4.2 Introduction

Considering the present broad focus on the identified barriers and facilitators to resident inclusion in research, with communication challenges both within and between relevant systems highlighted and particularly of interest, this chapter provides a shift from identifying barriers and facilitators to exploring stakeholders' views on a process which may be useful in modifying such factors. Findings from the studies reported in the previous chapters suggest that stakeholders recognise challenges in communication between different relevant groups and would be willing to engage in processes to improve it."

Advance Research Planning (ARP) has been suggested as a process to honour the research wishes and preferences of individuals who may lose capacity in relation to their inclusion in research [69]. Using principles of ARP, it may be useful to facilitate early discussions about future research preferences with care home residents, who are often considered difficult to recruit.

The views of different populations have been explored about the role that ARP activities may play in supporting preference-based inclusion in research, lending strong support for ARP as a mechanism for promoting autonomy [70, 71]. Research is needed to understand stakeholders' views about how ARP processes can realistically be integrated into care home settings. Understanding how care home residents can be best supported to communicate their research wishes and preferences could lead to the development of interventions to support engagement in important discussions. These could include discussions about preferences for participating in different types of studies, or particular research activities such as routinely collected data.

This thesis chapter reports a qualitative interview study which explored the views of stakeholders (care home residents, relatives, care home staff, other HSCPs, and researchers) about care home residents' opportunities to participate in research and how best to encourage early discussions about residents' future research participation wishes and preferences. The chapter builds on the findings and questions resulting from the previous scoping review reported in Chapter 2 and the survey study reported in Chapter 3.

4.2.1 Chapter aims and objectives

The aim of this chapter is to inform understanding about stakeholders' views on research participation and ARP for care home residents. This will provide evidence to inform the next steps of the project which include the development of an engagement support intervention for care home residents.

4.3 Methods

Qualitative research has been described as a way of "*reaching the parts other methods cannot reach*." [248]. Resulting from theoretical perspectives such as phenomenology, qualitative research seeks to understand social phenomena from an individual's own perspective; *"the important reality is what people perceive it to be."* [248]. Alongside good research design and appropriate data collection and analysis, qualitative research can help support understanding of a particular phenomenon [249].

Semi-structured interviews are conversations led by a researcher with a pre-determined set of questions and an appropriate knowledge base to guide the conversation [250]. Creating a space in which the participant feels safe and able to share their personal experiences is an important goal of this interview style [250]. Semi-structured interviews provide the interviewer with the flexibility to tailor the interview at an individual level to enable richer data collection, and the autonomy to delve deeper into ideas raised during an interview whilst still maintaining focus on a topic, proposing a primary benefit of this qualitative research method [251, 252]. For these reasons, semi-structured interviews were deemed most appropriate to achieve the aims of this chapter above and beyond alternative methods such as focus groups, through which interactions between the group are a focus.

Thematic analysis can be used to identify, theorise, and report themes within data [80, 249]. As a widely used qualitative research method, thematic analysis is valued for its flexibility and accessibility, allowing researchers to explore data and draw meaningful interpretations [80, 249]. With its afforded 'theoretical freedom', thematic analysis presents a qualitative research method that can be used widely across research areas, proving a particularly popular method in health services research [253].

Our interests, assumptions, and purposes shape the methodology we decide to use in research [254] and so, in the case of this present exploration, a qualitative semi-structured interview method was chosen and implemented with data analysed using a thematic analysis approach. Interview structure was essential to support participants, ensure efficiency, and ensure that the needs of the interview were met. Alternative data collection methods, such as focus groups, would not have been suitable due to practical challenges and the additional support needs for some participants [255]. Further, alternative data analysis methods such as discourse analysis or a grounded theory approach would not have best supported the present aim of exploring individual views and opinions in depth. It is possible that a framework analysis might have worked, however, this is a less inductive approach often best suited to larger samples than those included in the present work.

4.3.1 Design

Semi-structured interviews were conducted with stakeholders, either virtually or face-to-face, to enable in-depth discussions [76]. The researcher and supervisory team have combined experience of working in care homes, professional nursing qualifications, and close family members being care home residents. These experiences informed study design and analysis.

It was anticipated that approximately 20-25 stakeholders would need to be recruited. This sample size was based on the numbers anticipated to achieve sufficient saturation and information power (as determined by the research team) to address the research question and was informed by similar studies conducted previously (e.g., [118]).

4.3.2 Participants and recruitment

Participants were recruited through various routes, including contacting stakeholders who participated in the previous survey and expressed an interest in being re-contacted. Local care homes were contacted directly via email and phone calls and followed up with in-person visits. Researchers of on-going care home studies, found via the NIHR website (https://fundingawards.nihr.ac.uk), were contacted via email. Existing networks, such as ENRICH (England, Cymru, and Scotland) and social media (Facebook and Twitter/X) were utilised to recruit participants, and opportunistic recruitment of researchers was also conducted at relevant conferences.

Purposive sampling was carried out to ensure that the views of all stakeholder groups were sufficiently collected and able to be explored during data analysis. The use of alternative sampling methods, such as random or convenience sampling, would not have best aligned with the purpose and aims of the present study. Theoretical sampling is another alternative, which would be more robust and appropriate than random or convenience sample, but more useful alongside a grounded theory approach. However, in this stage of the project, I was not trying to develop a theory but rather explore the views of stakeholders. The use of purposive sampling also ensured flexibility and that participants were chosen for their ability to contribute valuable information aligned with the research aims.

4.3.3 Data collection

A pilot interview was conducted with a participant who was representative of a number of the stakeholder groups (relative, HSCP, and researcher) to test the interview acceptability, comprehensibility, and interview guide content (see Appendix 4.2). This participant was a colleague in the Division of Population Medicine at Cardiff University. Small amendments to the design and content were made following the pilot.

Care home residents were supported to participate through the provision of accessible information about the interview. Only participants with capacity to consent participated in interviews as the study focused on views about research in the event of future loss of capacity. Data collection was carried out between May and September 2023.

4.3.4 Data analysis

Interviews were audio recorded and transcribed. Transcripts were then checked for accuracy against the recordings and data cleaning and anonymisation were undertaken in order to remove any potentially identifiable information. Data were analysed following Braun and Clarke's [80] reflexive thematic analysis approach, supported by NVivo qualitative data analysis software (NVivo 1.7.1, QRS International).

The typical process of thematic analysis was carried out starting with data familiarisation. Following familiarisation, analysis of the first 10 transcripts was undertaken, including the identification of codes and the development of initial themes, with discussion with my supervisors. Following this, a random selection *(n=5)* of transcripts were sent to the supervisory team for review, along with an early coding framework. The researcher and supervisory team then met to discuss and refine themes. Advice was given to probe more specifically into some topics and to focus recruitment efforts on underrepresented stakeholder groups. The remaining transcripts were coded by the researcher and further development and refinement of themes was carried out iteratively through ongoing discussions with my supervisors.

In line with suggestions made by Guba and Lincoln [256], through work exploring interpretation of qualitative data, trustworthiness and rigour were achieved during the data analysis process through triangulation, reflexivity, and peer debriefing between myself and my supervisors, all of whom have relevant experience within this field.

4.3.5 Ethical considerations

This study received a favourable opinion following review by Cardiff University's School of Medicine Research Ethics Committee (SMREC ref. 23/29; see Appendix

4.3). Participants received an information sheet (see Appendix 4.4) and consent form (see Appendix 4.5) prior to the interview, as well as the opportunity to ask questions. Participants provided verbal consent before taking part in the interview, which was audio recorded in accordance with guidance provided by the Health Research Authority (HRA, [257]). Unique study ID numbers were allocated to participants to ensure anonymity, as well as the removal of any identifying information from transcripts prior to analysis. Further information about confidentiality, anonymisation, and personal data security were included in the participant information sheet (Appendix 4.4), as well as contact details should participants wish to ask any further questions.

4.3.6 Patient and Public Involvement (PPI) consultation

A consultation meeting was held virtually with the ENGAGE study's PPI group during which themes were presented and discussed. This was followed by a one-to-one discussion with a resident PPI member, who joined the PPI group in March 2024, at their care home to present the same information in a more accessible format. The purpose of the consultation was to gain insight from, and clarify, interview findings.

4.4 Results

4.4.1 Participants

A number of participants were members of more than one stakeholder group, reflecting intersections between personal and professional experiences. However, during qualitative analysis participants were grouped based on the stakeholder category they reported primarily belonging to.

Stakeholders who identified as a relative to someone living in a care home included relative only (n=4), relative with experience of conducting research (n=1) and relative and HSCP (n=1). Care home staff member roles included manager (n=1), senior carer (n=1), activities coordinator (n=1), and nursing care assistant (n=2). HSCP roles included General Practitioner (n=3), clinical studies officer (n=1), and clinical quality nurse (n=1). Length of interviews ranged from 4 to 31 minutes. Details of the participants (n=25) are presented in Table 4.1.

Table 4.1 Characteristics of participants of the interview study (n = 25)

	No. (%)
Stakeholder	
Care home resident	5 (20)
Relative	7 (28)
Care home staff	5 (20)
Other HSCPs	5 (20)
Researcher	3 (12)
Location of care home	
Wales	16 (64)
England	7 (28)
Scotland	2 (8)
Experience taking part in or conducting care home research	
Has research experience	8 (32)
Resident	0 (0)
Care home staff	1 (4)
Relative	1 (4)
HSCP	3 (12)
Researcher	3 (12)

4.4.2 Themes

Stakeholders’ views were iteratively organised into three themes: (1) We’re of no value to research; (2) Research is difficult; and (3) Advance research planning: good in theory, challenging in practice. A number of subthemes were also created and included: care home research as a priority to researchers and the community; residents’ perception of their value to research; communication and relationships;

positive views of advance research planning; and challenges of advance research planning.

4.4.2.1 We're of no value to research

4.4.2.1.1 Care home research as a priority to researchers and the community

Stakeholders from all groups expressed the view that care home research, and care home residents, do not seem to be a priority for researchers or the wider community. This included the view that the research community consider residents to be less valuable participants in research, perhaps because of views about their age or that they have a less meaningful contribution to make.

"It's because they're older, aren't they. They aren't focused on as much as other age groups." Relative, P019.

"I don't think there's the motivation to support them in the care home, and there isn't the dynamism, or the need – the want – to make their voices heard in that particular way." Care home manager, P019.

"I don't think the research community as a whole think that people living in care homes – well they don't even think they should [be included] – they would be a valuable participant in research." HSCP, P012.

An experience shared by one HSCP around recruiting residents to research suggested that recruitment of this population is difficult and that researchers do not have the time or resources to prioritise their recruitment.

"When I was making a priority list [for recruitment] if I wasn't able to approach everyone, unfortunately the care home residents tended to be at the bottom of the list." HSCP, P007.

Participants also emphasised that the COVID-19 pandemic highlighted the paucity of care home research. Participants from all stakeholder groups shared the view that care home research has now become more of a priority because of the pandemic.

“I think [research in care homes] has taken longer to come onto the radar and obviously, COVID, really changed that and brought it much more into the spotlight.” Relative with experience of conducting research, P004.

A number of difficulties and challenges were experienced by care homes and residents during the COVID-19 pandemic. However, this led to the identification of an urgent need to prioritise care home research. Some stakeholders shared that they believed researchers and research funders are now placing greater importance on care home research and allocating more resources, meaning that more care homes are getting involved with research.

“The pandemic catalysed a lot of my involvement with the care home sector because we recognised the vulnerability of care home residents to COVID, and that persists.” Relative with experience of conducting research, P001.

“I’ll be honest, since sort of COVID we’ve started getting involved in research.” Staff member, P002.

The experience of COVID-19 also seemed to bring into sharp relief the previous neglect of research in the care home sector.

“With the explosion of COVID and everything it really opened my eyes to the struggles that they have and the fact that they get forgotten and I find that really sad.” Researcher with 29 years of research experience prior to getting involved with care home research, P014.

4.4.2.1.2 Residents’ perceptions of their value to research

References to residents’ feelings of disempowerment and a lack of autonomy were apparent throughout the interviews. Residents repeatedly suggested that they believed they were not worthy enough to take part in research and that they, or their views, would be of no use to researchers. One resident seemed to believe that their input would not be valuable because they were no longer typical of other members of society. One member of staff made a comment that suggests other stakeholders are aware of this feeling too.

“I think I’m past that age.” Resident, P016.

“I imagine it is because one feels that you’re no longer your usual self and what use are you to anybody else.” Resident, P016.

“They feel almost they’re not productive to society anymore and they’re looking at ways in which they can feel a bit valued.” Staff member, 002.

Further, the influence of societal beliefs towards people with disabilities or those different to ‘the norm’ was apparent and was suggested to influence the way people perceive more vulnerable populations and their ability to contribute to research.

“People [automatically] think if somebody’s in a wheelchair, people speak to the person who’s pushing the wheelchair. There’s that thing of asking the professionals and relatives, rather than [the individuals].” Researcher, P013.

Residents’ shared experiences that they do not feel supported adequately in the care home environment by staff in regard to their usual care needs, let alone to take part in research or in promoting their own autonomy.

“I haven’t got dementia thankfully and I feel that some of the staff are inclined to treat me as though I’ve lost my marbles.” Resident, P020.

Some relatives also gave the impression that they themselves view their relative as no longer having the ability or means to take part in research in a meaningful way. Relatives’ poor confidence in residents’ ability to participate in research and/or potential perception about the purpose or intention of research, was apparent. Resulting from this was an apparent unwillingness to support their inclusion.

> *"He's got dementia so I don't understand how much he would be able to give a useful answer." Relative, P024.*

4.4.2.2 Research is difficult

Some residents, relatives, and staff shared a perception that research is difficult and not for everyone. There was a general desire for more opportunities to be shared, and willingness to take part in research should it be offered, but this seemed to be hindered by the perception that research is difficult.

> *"Yeah, if it was easy." Resident, P021.*

Further, there was consistent reporting of a lack of awareness of care home research opportunities for care home residents, relatives, and staff members to take part in research, as well as the idea that these groups feel remote from those who conduct research, and from science.

> *"Absolutely not, no. In fact I would have said that it [research] was an almost completely alien idea to the care home staff." Relative, P010.*

4.4.2.2.1 Communication and relationships

Closely linked to stakeholders' understanding and beliefs about who research is for, and what research participation entails, was the overarching notion that both communication and relationships between stakeholders can be poor. Ways to improve the sharing of opportunities between stakeholders were suggested during interviews, including the importance of tailoring communication to ensure that it is effective and meaningful to each potential participant.

> *"It's not easy when you're trying to meet lots of people's needs because you don't want to dumb it down. Our residents a lot of them have been doctors, teachers, they've been quite high professionals, and still have that level of understanding but then others don't or because of difficulties they are slower to process the information." Staff member, P002.*

Around half of stakeholders, including residents, relatives, and staff members reported never having been approached to take part in research.

Suggestions made for improving communication and relationships included providing opportunities for residents and relatives to meet to discuss research opportunities and participation. Stakeholders also suggested that being involved in research, in any form, can ignite an interest to get involved. Interviewees suggested that study recruitment would also benefit from more flexible approaches to recruitment and the formats in which research opportunities are presented to potential participants.

> *"It takes ground working, relationship building, most importantly I would say." Relative, P010.*

> *"I don't think [researching in care homes] is the most natural thing to do but then I think it only takes you to get involved with one set of research involving care homes to understand that it could be made much easier for them [care home residents] and for the researchers if there was a better understanding of what was needed." HSCP, P009.*

4.4.2.3 Advance research planning: good in theory, challenging in practice

4.4.2.3.1 Positive views of ARP

Importance of ARP and the potential benefits for all

Generally, stakeholders who reported having no experience of research had positive views towards ARP, discussing the importance of residents having the opportunity to discuss research, as well as the value of researching the underrepresented care home population.

"I've got a firm belief that people who have dementia should and could still be involved in research. Just because somebody has lost capacity doesn't mean it's all or nothing, they can still decide to be involved in research, should they wish to be, just because it's difficult we shouldn't not do it." HSCP, P012.

Further, stakeholders from all groups highlighted the importance of residents being able to share and document their wishes for future research participation should they lose capacity to make such a decision in the future. Stakeholders acknowledged the importance of becoming aware of residents' research wishes and preferences and the possibility of implementing these in the future, should they need to. The potential benefits of ARP for residents seemed to be particularly important to relatives and staff.

"It's nice to have their thoughts." Relative, P006

"At least they would have had their wish before they've gone too far [lost capacity]." Staff member, P015.

"That's a good idea because people's capacity can vary, as time progresses, we can keep on fulfilling that wish. We know that this was once important to them." Staff member, P019.

Further, the benefits of ARP, including improving the ability of researchers to identify and recruit participants, was discussed by stakeholders with experience of recruiting care home residents and conducting research.

"It would be very useful to have that early engagement with them." HSCP, P003.

"It makes it a lot easier if they have already given their permission for that." HSCP, P007.

Another potential benefit of improving recruitment of residents through implementing ARP was offered by a relative:

> *"There's everything to gain to get it right, and whatever the average expectancy of a care home resident would be, that's how many extra years that country gains of potentially enrolling that person." Relative, P001.*

Recommendations for successful implementation

Stakeholders were asked about how and when early discussions about ARP would be best implemented, as well as who with. A powerful answer came from one resident: *"When they still have a voice."* Advice and suggestions were given about how these conversations could be successful and feasible, but primarily the focus was placed on how, when, and by whom the question should be raised.

A number of residents considered that discussions about research participation would be appropriate during conversations about other preferences, such as their care needs, upon entering the care home. There was some agreement with this from other stakeholder groups.

> *"At least a sensitive discussion, a tiny discussion, on entering the care homes with either the resident, the patient and/or their nominated informal carer, next of kin, I think that's key." Relative, P001.*

> *"It's fine when people go into a care home, in the first week or so, have a discussion and say, we're a care home who likes to take part in research, and we like everyone to have the chance to participate in that. Do you think you'd be willing to say that if a research project comes up, we can talk to you about it and decide whether or not you'd like to?" Relative, P010.*

> *"It could be built into their care plan." Staff member, P019.*

“It makes sense to have a conversation like we do, you know, with advance care planning, things like their wishes, do not attempt resuscitation orders, etc. Could this be added as a potential extra thought?” HSCP, P009.

“It would be nice, if it was part of the whole admission process, that you talked about future wishes for your health, future wishes for your data, future wishes for taking part in studies.” Researcher, P008.

There was a common view between stakeholder groups that family members should be involved in such discussions with residents, but for different reasons. Residents generally felt that having these conversations with family members or someone who was able to give them all of the necessary information would be best. Relatives’ answers varied with some thinking that residents needed family members present to ensure that information is shared in a way their relative can understand, but also expecting researchers to be present in order for any questions to be answered. Care home staff mostly stated that family members should be included, with one staff member stating that it should be *“somebody they trust at the end of the day”,* and that this may not be a relative for everyone. HSCPs and researchers’ answers varied also, with some suggesting that these conversations should include whoever is most important to the resident, and others emphasising the importance of researchers and/or senior care home staff being present and involved.

“I suppose somebody who is able to talk to lots of different people and are able to have an approach which can appeal.” Resident, P016.

“My daughter I would say.” Resident, P021.

“It would obviously need to be somebody who asks the right questions first time. But then I do think there should be another person present who the resident feels comfortable with. So not necessarily anyone to do with the research, but a family member or a carer.” Relative, P023.

> *"The relatives definitely … because they are more comfortable. They can explain everything, they are family so they know exactly how to explain, and if they actually do want to consent or not." Relative, P006.*

4.4.2.3.2 Challenges of ARP

Concerns about capacity and residents' ability to engage in ARP

Comments from non-resident groups suggested that relatives may underestimate the capabilities of residents.

> *"I don't have a lot of confidence that [residents] will have the brain space to be considering it." Relative, P024.*

Researchers discussed the likelihood of residents' cognitive abilities changing over time. A relative contributed a similar thought relating to concerns about changes in residents' abilities and needs at a later time. This raises a concern shared by stakeholders that any decision made early on may no longer be reflective of the resident at a later timepoint.

> *"[A resident doesn't] necessarily know which kind of cognitive function [they] might have, so [they] might consent to something and then by the time it actually comes round to it, it's very distressing." Relative, P023.*

Other stakeholder groups made comments related to residents' ability to make decisions about their own research participation and understanding of consent.

> *"Some of them [residents] won't understand the concept of capacity." Researcher, P008.*

Staff members suggested that being involved in facilitating discussions about ARP may be difficult due to work pressures, linking with other comments identifying care home staff as possible barriers to the inclusion of residents in research.

“Discussions might make residents more anxious to be honest with you, or more unsettled.” Staff member, P017.

Further, those with experience of conducting research were more wary or hesitant about ARP in terms of its implementation feasibility.

“It’s quite difficult to do. I mean, I like it in theory … I don’t think it would work in practice.” Researcher, P008.

“I got kind of caution over it.” Relative, P004.

Further, concern was given to the potentially sensitive nature of the topic from stakeholders. A number of respondents commented on the distress that having conversations surrounding potential future incapacity may cause to care home residents, especially considering the hypothetical nature of the topic.

“I think the idea of talking to somebody about an uncertain future, and what they might want to do, when things are potentially worse than they are now, it’s quite ethically complicated, in terms of how distressing it might be to imagine that uncertain future.” Relative, P004.

However, this view was not shared by residents themselves who thought that residents would be happy to have these conversations.

“Yes, I think they would be [happy].” Resident., P016

Binding element of ARP

One main contested point in relation to ARP was whether such conversations would provide a binding contract from which residents, as a ‘vulnerable’ population, may be taken advantage of at a later date. However, a mention of it being ‘hard’ to get consent for residents may reflect an additional concern for the resident’s wellbeing or highlight the likelihood of it requiring more effort from stakeholders in supporting residents.

> *“I suppose it gives that understanding about where that person is at that point in time, but that doesn’t necessarily mean that it reflects where they are later on when they don’t have capacity.” Researcher, P013.*

> *“There is a difficulty there because [residents] are perhaps vulnerable, and getting consent for vulnerable people is hard.” Relative, P024.*

Further, an underlying belief that an advance discussion would commit them to a prior decision, over and above their preference and needs at that time was apparent.

> *“I don’t think you can get a blanket agreement to participate in research for all kinds, I think that wouldn’t be ethical to consent [in advance].” Relative, P010.*

Many stakeholders suggested that a general agreement to participate can be ethically obtained from residents during an early discussion about research wishes and preferences. However, this would need to be revisited by the consultee on a case-by-case basis as new research opportunities arise in order to assess the abilities and suitability for the resident at that time, whilst considering the knowledge that the resident had previously given overall support.

Implementation challenges

Participants identified potential difficulties and challenges that may be encountered in the implementation of ARP, including concerns over the feasibility of having these discussions. Factors such as access to care homes and residents at an appropriate time, the language used, and turnover of residents, may pose barriers to consistently and effectively facilitate discussions about ARP.

> *“It’s not like you could just turn up to a care home every week and try and speak to anyone who’s entered newly.” HSCP, P009.*

> *"Having questions that are inclusive of the likely eventualities like losing capacity and what that means in lay terms, [for example] my nana would not know what capacity means even if you explained it to her a thousand and one times." Relative, P001.*

Further, relating to issues around communication and relationships previously mentioned, challenges were identified around who the "right person" to ask such questions, or facilitate such discussions, would be. Trust in the person asking questions and facilitating a potentially distressing topic of conversation seemed to be another important factor for one relative.

> *"It's not just about content, it's also about the execution, the format of delivery and who's the right person, you run the risk then of there just being a check box exercise where people are talking about it half-baked." Relative, P001.*

4.4.3 Patient and Public Involvement (PPI) Consultation

Overall, discussions held with PPI members supported, and strengthened, initial theme development. Members shared important views and experiences related to the themes and supporting quotes.

All members discussed their initial thoughts about the three themes identified, and their titles, agreeing that they could understand how they would arise in such interviews. Some sadness was expressed about the 'We're of no value to research' theme, with members sharing that they can understand how it arose but wish residents did not feel this way. The PPI member who holds both relative and research experience immediately stated that we need to make research less difficult in response to the 'Research is difficult' theme. Another offered their own experience with advance care planning and suggested the 'Good in theory, challenging in practice' theme is to be expected due to difficulties in communicating exactly what is being asked to stakeholders, and understanding exactly what it is residents want.

4.4.3.1 We're of no value to research

One PPI group member who works in a care home discussed the difficulties faced for residents to have their voices heard when there are relatives with such strong opinions who think they know best for their resident-relative and override their own decisions even though they are capable of making them and have capacity. They voiced the importance of changing this because residents tend to give up and let relatives make the decisions for them.

Both the PPI group members who are relatives shared their own experiences of the COVID-19 pandemic and its impact on their relative residing in a care home, as well as reflections on research during that time and after. One member shared that their relative's care home seemed very keen to help with COVID-19 research and were asking relatives to get involved. Another expressed that during this time the treatment of care homes and care home residents was *"horrific"*, and that it highlighted inequalities for the sector. However, they felt that care homes are now becoming less important again.

When discussing this theme, PPI members spoke about apparent differences in primary vs secondary care and that they believed care homes seem to not quite fit in any category. For example, they considered that primary care settings appeared to benefit from 'research ready' registers to sign up to and that community care settings might benefit from something similar.

4.4.3.2 Research is difficult

One PPI member who works in a care home shared that they *"agree completely"* with this theme and that, when research is mentioned, a lot of staff would immediately think of laboratory research and not be interested. This highlights the necessity of educating stakeholders about different types of research and exactly what participation would entail.

One PPI member, who is both a relative and researcher, discussed the importance of incentives to encourage participation, due to the effort and time it requires, and that other health care settings are able to recruit because they have appropriate renumeration. With experience from a unique perspective (as both a relative and researcher), they shared that they often act as a ‘go-between’ for their relative’s care home and research. They felt that staff consequently see them as *“less threatening*”, not being someone *“with three heads”,* and someone they can relate to. Another PPI member who is a relative reflected that there tends to be a difference in education level between staff and researchers which may cause staff members to feel intimidated and act in a hostile way towards researchers. Overall, discussion around an ‘Us vs Them’ narrative stressed the importance of developing and maintaining relationships between stakeholders to improve research inclusivity.

4.4.3.3 Advance research planning – good in theory, challenging in practice

Reflecting on their own role as Power of Attorney (POA), one PPI member suggested that a question about research wishes and preferences may sit well within the ‘health and welfare’ section of the POA process, but this needed to improve all stakeholders’ knowledge about the full scope and nature of research. One PPI member, who is a relative, raised the potential cognitive benefits of being involved with research for residents who may otherwise not engage with traditional care home activities. Research may be particularly appealing when it is considered to be meaningful and residents want to feel as though they are being productive and contributing to society.

Challenges surrounding the feasibility of asking everyone who goes into a care home about their research wishes and preferences were shared by care home staff PPI member, and one relative member stressed the strong protective desire relatives feel over their family member residing in a care home. A suggestion was offered that discussions about residents’ preferences may be better approached by a GP because of the existing relationships, and such questions are to be expected in a health care setting.

To conclude, PPI members reflected that ARP is a delicate but important topic, and not knowing what future research opportunities will be could make it difficult to have such conversations and make decisions. Research within care homes needs to start with relationship and trust building so that such conversations can be facilitated. The suggestion of a communication intervention being developed to support residents to share their future research wishes and preferences was popular and a sensible challenge to approach: *“the communication needs to come first.”*

4.5 Discussion

Facilitating early discussions with care home residents about their research participation wishes and preferences has the potential to benefit research participation, and thus representation, of a population with complex health and social care needs at risk of their needs being left unmet. There is an apparent need for more research that recruits from care homes, not only for research specific to care home residents but also studies for which care home residents meet inclusion criteria.

Whilst this is the first study to explore advance planning for research in the care home setting, the wider literature looking at translating advance planning for research participation into practice also discusses optimum conditions in which stakeholders believe implementation would be most successful. In a survey of public and professional stakeholders, Shepherd et al. [71] report that participants discussed the importance of with whom, and when, discussions would be most successful, as well as other crucial contextual and resource requirements that would be optimal to implement advance planning discussions in an acceptable and feasible manner. Further, stakeholders of a workshop held by Ries et al. [69], focusing on research involving people with dementia, included suggestions of utilising a ‘phased approach’ with this population, and also the importance of raising awareness of advance planning for research, in line with the findings of the present study.

Furthermore, the present study findings are consistent with reviews of care home research which report that communication and relationships often act as barriers to the inclusion of care home residents in research [52, 58]. Additional previous research findings have suggested that superficial relationships are often seen between stakeholders in care home research [49].

4.5.1 We are of no value to research

Stakeholders discussed the importance of research including the care home population but also the challenges of doing so, in line with previous studies [52, 58]. With regard to the apparent importance, yet low priority status, of care home research, stakeholders discussed the impact of the COVID-19 pandemic. Their perception that care home research has become more of a priority post pandemic aligns with recognition of the importance of improving research in care homes by government bodies. For example, following the pandemic, an announcement was made by the UK Health Security Agency of a data sharing scheme for over 500 care homes in England to monitor infections in care homes [258, 259].

Further, beliefs about research importance, as well as shared recruitment experiences by stakeholders, suggest that in an attempt to be efficient with resources researchers opt to recruit less ‘hard to reach’ populations. It is important to recognise that research participation, whilst often viewed as burdensome, is a right which should not be denied due to residence at a care home. Rights-based approaches are being established to promote inclusivity for consent and inclusion in people living with dementia in research in countries such as Canada (e.g., [260]). Furthermore, the resulting lack of inclusion may facilitate residents’ feelings that they are less valuable to research or to society in general, identified in this study, which has also been reported in other studies [58]. Awareness of this may be especially difficult for a generation considered to place importance on contributing to society, which has also been linked to residents’ sense of purpose [261]. Additional findings of resident disempowerment and lack of perceived autonomy in this study align with previous care home research which reports that, in some cases, experiencing a lack of support to make their own decisions can result in residents giving up trying to express their voice and agency [50].

It is possible that society instils the narrative that when people get older, or in any way impaired, they are automatically less able to take part in activities they once could. Experiences of being overruled, despite knowing they are capable, may lead to residents feeling that they are no longer in control of their own lives. The resulting apparent lack of interest in getting involved in research has been reported in a review of barriers and facilitators to the inclusion of this population in research [58], and may be due to the feeling that events are out of their control, explained by theories such as learned helplessness [262]. It is possible that the implementation of advance planning for research in care homes may increase residents' perceived control over their lives and thus improve feelings of autonomy too, in line with principles of SDT [263]. Further, such feelings may be due to prejudiced views about this population and the wariness and hostility towards researchers sometimes seen, as suggested by a PPI member who is a relative. These findings build on other research that residents share feelings of not belonging and that poor relationships are factors which consequently facilitate social loneliness for care home residents [49]. Fricker's [264] philosophical framework of epistemic injustice lends support to this, explaining that epistemic injustice manifests as an exclusion of marginalised and oppressed people from being heard and understood by others, as seen with the care home resident population and their under-representation in research.

The feelings of disempowerment shared by residents in this study, as well as their perceived lack of autonomy, are consistent with findings of care home residents' views in previous studies [58]. As well as beliefs about care home research and resident priority, it is possible that other stakeholders, for example relatives, may play a part in facilitating residents' feelings of disempowerment and perceived lack of autonomy. The shared experience, by PPI staff member, of relatives overruling resident decisions, despite having capacity, supports this suggestion as do other reports of such events in research (e.g., [189]). This experience of being overruled, despite knowing they are capable, may lead to residents feeling that they are no longer in control of their own lives. Experiences of feeling unsupported to make their own decisions may reinforce a perceived lack of autonomy in residents, and is some cases results in residents giving up trying to express their voices and a lack of agency [50]. Such a phenomenon can be explained by Seligman's [262] theory of Learned Helplessness, which suggests that Learned Helplessness occurs because an individual perceives events to be out of their control as a result of experiences. Research has used learned helplessness to explain depression-like symptoms in older adults which are highly prevalent in care home settings [265]. It is possible that the observed cognitive dissonance between relatives and residents' beliefs about resident capability may also facilitate learned helplessness, especially when considering suggestions that older adults are particularly sensitive to dissonance effects [266].

Furthermore, being treated as if one is incapable of decision-making and vulnerable may facilitate a self-fulfilling prophecy by which residents internalise others' beliefs and so become what they are believed to be [267]. Research has shown that when older adults perceive their independence to be removed, or believe others to have low expectations of them, they can begin to doubt their own abilities to look after themselves [268]. Such perceptions can lead to reduced capabilities and become self-fulfilling, causing both deterioration in health and cognitive ability [267-270]. Older adults' perception of their own autonomy has also been associated with level of life satisfaction [271, 272].

Self Determination Theory (SDT, [263]) states that if an individual's basic psychological needs of autonomy, competence and relatedness are not supported, that individual's wellness can be detrimentally impacted. Meeting these conditions forms motivation, and a lack of motivation coupled with feelings of not being in control of their lives may explain the apparent disempowerment residents feel as has been identified in this and other studies (e.g., [58]). Additionally, motivation is key in the pursuit of undergoing new skill learning, which research participation would be for many stakeholders. For older people it is suggested that learning may be motivated by intrinsic reasons, participating for the inherent enjoyment, rather than benefits or pressure [273]. Central to SDT is the idea that intrinsic motivation is driven by the satisfaction of the three fundamental human needs stated previously [214, 263].

4.5.2 Research is difficult

"Although participants made it clear that there were a number of difficulties in taking part in research, very often these were linked directly to the barriers discussed previously in the thesis. Explicit difficulties perceived by participants over and above these are something that I may have prompted further in retrospect. However, some participants did suggest the issue lay mainly with understanding about what research is, and what participation entails, and it would seem that not feeling understood by researchers because of poor communication and relationships may also have been a problem, adding to their difficulties."

Perceptions of research in general differed between stakeholder groups depending on their understanding and experience. Inconsistencies were identified between stakeholders' understanding of the different types of research and its aims, researcher motives, and who is likely to benefit from participation. This may explain the caution that many stakeholders showed and poses an area of improvement for future education programmes.

Throughout interviews it was apparent that resident, staff, and relative stakeholders do not understand the world of researchers or academics. The apparent lack of interest in getting involved with research observed in both this study and other studies (e.g., [21, 130] may also be a result of an 'Us vs Them' perception. Social Identity Theory (SIT) [274] suggests that prejudices and discrimination occur naturally when an individual categorises someone else as a member of an out-group. This may explain the wariness towards researchers suggested by one PPI member who is a relative. It may be possible that some stakeholders may feel intimidated by other groups who they are unable to identify with because of a belief that both groups do not understand each other's worlds.

Unsurprisingly, difficulties in communication and challenging relationships between stakeholders were reported and alluded to throughout interviews in this study. These findings are consistent with reports from reviews of care home research which report that communication and relationships often act as barriers to the inclusion of care home residents in research [52, 58]. Research by Buckley et al. [49] suggests that superficial relationships so often seen between some stakeholders in care home research, as well as feelings of not belonging, are factors which consequently facilitate social loneliness for care home residents.

Further, Social Exchange Theory (SET) [275, 276] posits an explanation for the challenges of developing and maintaining relationships between stakeholders in care home research. SET describes the social behaviour in the interaction between people and focuses on a cost-benefit analysis to determine risks and benefits. It may be the case that care home staff and relatives only see the risks of participating in research, in terms of costing their time and resources with little benefit. This may particularly be true having seen negative portrayals of the sector shared by the media when ‘outsiders’ visit. SET argues that negative relationships occur when the costs outweigh the benefit. Increasing awareness of the possible benefits to all from taking part in research may facilitate greater relationship building and thus improve well-being for residents and quality of life for all as a result.

The Senses Framework by Nolan et al. [277] proposes six senses that are prerequisites for good relationships in the context of care and service delivery. Security, continuity, belonging, purpose, achievement, and significance are the essential senses suggested and it is apparent in the present study that many stakeholders do not connect with one or more of these senses. The framework places importance on each individual in a relationship experiencing a sense of significance and feeling that they matter in that relationship. It may be the case that collaborative working and co-design practices would be the most effective way of including stakeholders in research so that all parties included feel that they are equal, also possibly reducing the ‘us vs them’ narrative identified.

However, whilst difficulties in communication were discussed repeatedly, some interviewees also mentioned the importance of improving communication between stakeholders, in terms of language use, accessibility, sharing of information, and how developing relationships can facilitate trust between stakeholders. It was apparent that trust is an essential component to stakeholders, particularly for positive outcomes when encountering research as a potentially novel concept for some. Relational Cohesion Theory connects trusting relationships to successful implementation and emphasises that these relationships contribute to increased resilience and commitment in the face of challenges [278], which research may be perceived as by some stakeholders.

The importance placed on improving communication channels between stakeholders suggests a willingness to change and so may posit a target for researchers to develop an intervention or tool which could be of benefit to research uptake.

4.5.3 Advance research planning – good in theory, challenging in practice

Opinions about ARP participation differed between stakeholders, most noticeably between those with and without experience of designing or conducting research. Those without these experiences generally reported an enthusiastic view towards ARP and offered suggestions about how they believed it could feasibly and successfully be implemented for care home residents. Opinions about optimal conditions for these discussions to happen were freely given, including views on the best time, persons present, and delivery of questions encouraging discussions. The benefits of research participation to residents appeared to be the most important factor for relatives' positive opinions, which is consistent with reports that the use of incentives may improve research recruitment and retention in trials (e.g., [279]). This suggestion is in line with a benefit-cost framework of motivation proposed by Studer and Knecht [280] which states that expected benefits and costs of performing an activity determine the motivation for performing that activity, as well as the theory of cost-benefit analysis [240].

Further, discussion by residents, relatives, and staff members around additional benefits of research participation included the potential of providing meaningful activities for care home residents who may not engage with traditional activities offered. For a generation who often hold a strong sense and importance towards helping others and contributing to society, research participation and its benefits could provide a much more meaningful and stimulating activity for some. As already identified, residents typically have few opportunities to make personal decisions or exercise control over their life. For some residents, presenting the opportunity to engage in research may appeal to their interests and values and thus provide meaningful activities, reducing negative consequences of being in a care home such as boredom and loneliness [281, 282]. Being able to make decisions about such opportunities has the potential to empower residents and increase their perceived autonomy which may improve wellbeing and quality of life too.

Many comparisons to existing advance planning processes were made by all stakeholder groups. ARP was generally accepted as being another useful conversation to have when planning for end of life. Ries et al. [69] report that in many areas of life, advance planning is encouraged as a matter of law, policy and practice. However, research planning is typically neglected. Briggs [283] discusses the benefits of an advance care planning program, Respecting Choices. Evidence of successful implementation of advance procedures, coupled with the positive attitudes shared by stakeholders in this study around giving care home residents the opportunity to share their research wishes and preferences, begs the question of why it could not also be a successful and useful formal process.

Concerns surrounding residents' ability to engage in discussions were openly debated during interviews, with strong opinions shared mostly by relatives. A sense of importance was placed on making sure that their relative living in a care home was not taken advantage of by researchers, as well as the apparent concern that their loved one would make a decision that is not aligned to what they would deem 'best' for their wellbeing. Whilst typically coming from a place of love, this overprotective and cautious behaviour may reinforce residents' perception that they have little control over their own lives and decisions. In a paper by Lawton and Brody about the assessment of older people, they discuss the possibility that relatives often infantilise or underestimate the older person in an attempt to psychologically deal with their own needs [284]. As a result of this, as well as feelings of guilt or an inability to accept dependency needs, relatives may make decisions on behalf of the older person that are not necessarily in line with their abilities.

Furthermore, apparent from some participants' comments was the need to consider the ethics surrounding the 'fairness' of asking care home residents to consider a potentially sensitive topic of potential future incapacity. However, when asked directly, care home resident participants shared that they did not believe asking questions around this topic would be a problem. It is however important to consider the potential risks of sensitive research with vulnerable populations to ensure that the research respects residents' rights, autonomy, and dignity whilst minimising the risk of harm.

Further, concerns about the long-term implications of discussions about ARP were raised by stakeholders. Perhaps due to variations in beliefs about what the process would entail, many stakeholders shared concerns over the potentially binding contract, or cementing of decisions made, should the resident express interest in being involved in research in the future. Erroneous beliefs that outcomes from early discussions about research wishes and preferences would overrule the wellbeing, needs, wishes, and preferences of the individual in the future, must be put right in order to ensure true understanding of the motives, and benefits, of ARP.
General education about research, including the possible types and aims, as well as the aims of advance planning discussions need to preface any implementation or facilitation of these early discussions, with communication again being key. As discussed by stakeholders in this study, information shared with stakeholders should be tailored and accessible to each stakeholder group and be a supportive tool to help individuals understand all of their options, and make informed decisions based on these.

4.5.4 Strengths and limitations

This qualitative interview study used a reflexive thematic analysis approach with iterative data collection and analysis which enabled it to provide a richer and broader understanding of participants' views and experiences. The modest sample size meant that participants may not reflect the broad range of perspectives including people from different socio-economic, educational, ethnic, and geographical backgrounds. This also meant comparing and contrasting views from different groups of people in a systematic way was not possible. However, enough relevant information was shared by the each of the stakeholder groups, lending support to the achievement of 'information power' [285]. The good representation of each stakeholder group was also supplemented by additional input from the PPI group who provided their insights through a discussion about the initial findings and so the conclusions were collaboratively developed.

Whilst precautions were taken in the present study to avoid this, a potential limitation of thematic analysis is that individual voices can get lost, especially when many stakeholder groups were included. In order to reduce this, stakeholder group names were used when referring to views shared by specific groups and presented quotes with anonymised participant ID numbers to support readers in following individuals' contributions from interviews throughout.

I recognise the difficulty experienced in capturing the voices of care home residents with research experience. I faced challenges recruiting residents with research experience as they were cautious about the formal consent process despite conversing happily and freely “off the record” before consent was formally audio recorded, which has been reported in other studies [286]. In order to include and supplement the views of residents, I recruited a resident with experience of research as new member of the PPI group. In doing so, I was able to incorporate their views and input in this study.

A participant sample of 25, representing five stakeholder groups, may present challenges around generalisation. However, recruitment was iterative and stopped when themes were fully saturated with rich data. The themes identified were also supported by other literature as discussed in this thesis.

4.5.5 Future research

Understanding who stakeholders believe would be best to support revision of consent, including revision based on the type of research opportunity at that time or interpretation of previous expressed preferences in relation to present needs, would be a useful next step for researchers in order to compliment this research area. Further research is also needed to explore the views of regulators such as ethics committees.

General education about research, as well as the aims of advance planning discussions would need to preface any facilitation of early discussions, with communication being key. In line with the findings of this study, paired with previous advance planning research, information shared with stakeholders should be tailored and accessible to each stakeholder group and be a supportive tool to help individuals understand all of their options, and make informed decisions based on these. In line with study findings, recommendations to enhance opportunities for residents to express their research wishes and preferences can be found in Table 4.2, and a resulting infographic in Appendix 4.1.

In addition, it is important to consider that advance planning for research participation would need to operate within the UK policy framework governing health and social care research (i.e., the NHS HRA, [287]), considering recommendations within proposed principles including scientific and ethical conduct, safety, and benefits and risks.

Further, reflecting on my experience of conducting the present study, it is important to consider the ethics surrounding the boundary between being a participant and being a PPI representative. These roles require our stakeholders to take on different perspectives – a personal perspective as a research participant and a community perspective for a PPI member. Switching between these roles may be difficult or perhaps not fully understood for our stakeholders. Future research may want to consider targeting the processes by which researchers are required to recruit and the suitability of these (i.e., consent procedures) to the care home population.

In the final part of this PhD, a communication intervention to support residents to engage in early discussions about their research wishes and preferences is developed.

4.6 Summary

This chapter has discussed the process of the qualitative interview study which was informed by previous stages of this project as reported in earlier chapters of this thesis. Stakeholders expressed the importance of care home resident representation in research but also recognise a number of barriers to their inclusion including communication difficulties. Due to the greater likelihood of residents losing capacity to consent at a future timepoint, early discussions about research wishes and preferences could benefit not only them, but their potential future consultees, researchers, and the generalisability of health care research findings to the wider care home population going forward. Internationally, planning ahead for research with other ‘vulnerable’ populations is of huge importance. Facilitating such discussions with care home residents is a complex process and requires support from other individuals who hold their trust. The findings of this study can contribute to the development of an adaptable communication tool needed to support discussions and decision-making with care home residents about their wishes and preferences for future research participation.

Table 4.2 Recommendations to enhance opportunities for residents to express their research participation wishes and preferences

Recommendations by stakeholder group
Residents 1. Residents may benefit from having greater awareness about research generally in order to maximise their understanding about what participation entails. 2. Residents should be supported to express their research wishes and preferences in advance, but also at the time of any proposed research, considering that these may change with time.
Relatives 3. Relatives may benefit from greater awareness about research generally in order to maximise their understanding about what participation entails. 4. Relatives should support residents to share their own views, wishes, and preferences about taking part in a study rather than making assumptions based on their own views. 5. If consenting on a resident’s behalf, relatives should base their decision on the resident’s research wishes and preferences rather than their own. 6. Relatives should be supported to engage in processes which allow residents to share their own views, wishes, and preferences.
Care home staff 7. Care home staff may benefit from greater awareness about research generally in order to maximise their understanding about what participation entails

Recommendations by stakeholder group

8. Care home staff play an important role in the sharing of research opportunities, recruitment of residents, and retention of residents in research – staff can help to bridge the gap between researchers, residents, and relatives by helping to share positive messages about research.

Other Health and Social Care Professionals

9. Health and Social Care Professionals who are involved with care homes can help raise awareness of opportunities for care home residents to be involved in research projects.

Researchers

10. Researchers should consider how to ensure that residents have an equitable ability to participate in research which should not be denied due to residence in a care home.
11. Researchers should consider how to include care home residents in a broader range of studies not only for research studies specific to care homes.
12. Researchers should consider how to maximise opportunities for residents to express their views about research.
13. Researchers should ensure that discussions about research are relevant, appropriate, flexible and tailored to the resident's communication needs.

Regulators

14. Regulators should consider the importance of including care home residents in research and allow for reasonable adjustments to be made to support their inclusion.

4.7 Reflections

Whilst not without its challenges, the overall experience of designing this interview study, recruiting participants, conducting interviews, and data analysis and interpretation was enjoyable and offered opportunities for me to develop a number of skills which will benefit my research career going forward.

In order to ensure I had the skills to effectively and efficiently analyse the data I collected from interviews, I benefitted from training on qualitative research methods. I also attended two training sessions on how to use NVivo software to support me in my analysis of interview transcripts which aided the organisation of my data, the development of my codebook, and my interpretation of the data.

I found conducting the interviews, and facilitating a discussion on a topic that was novel to most participants, truly enjoyable. Discussions with participants both before and after the interviews opened my eyes to the abstract, ‘meta’ nature of my research about research and allowed me to tailor my explanation of the research to each stakeholder group. The views shared by participants both benefitted my understanding about stakeholders’ views and beliefs on this topic and increased my interest further. I believe that including the choice to take part in an interview either virtually or in-person was a great benefit as it allowed me, as the researcher, to be flexible, cater to the preferences of participants, and potentially reduce research burden for participants.

Further, it was apparent that residents in particular found taking part enjoyable and upon reflection, because of this, bringing the conversation to an end was difficult. Because of this I have questions around what it means for residents when participation ends, and how to sensitively and ethically end participation with those who you build a relationship with.

Relatedly, I found that during both the development of the study and when carrying out participant interviews, I was able to refer to the recommendations for researchers to overcome challenges of care home research I developed as an output and infographic from the scoping review I conducted at the beginning of this PhD thesis. I made sure to follow my own recommendations, including developing relationships with care home staff, spending time in the care home away from conducting research, and providing active appreciation through feedback, which I believe helped me overcome some of the common challenges and barriers apparent in similar research in care homes/with care home residents.

Further, whilst aware of common barriers to the inclusion of care home residents in research and conscious to focus my efforts on engaging in ways to facilitate inclusion, I did encounter recruitment challenges. As I found in a previous stage of this thesis (Chapter 3), getting initial responses from care homes proved difficult. The recruitment of other stakeholder groups seemed much simpler which I believe is because of the use of social media and confidence in using virtual meeting resources. The receipt of a voucher in recognition of their time seemed to be a huge incentive for other stakeholder groups too.

More memorable interactions with care home residents included visits that resulted in no data collection, despite previous expressions of interest in taking part. One resident expressed a lack of interest in talking to me because of my age and that I would not understand her because I'm "from another generation." In my previous work I had considered the age barrier residents sometimes face in being recruited for research, but I had not considered the influence that my age might have as the researcher and interviewer. Another visit consisted of over an hour of pleasant conversation between me and a resident, including both general chit-chat and discussion about the study and participation, but did not result in actual participation from the resident. Having discussed everything necessary about the study and asking the resident if they were happy to get started, I moved on to the consent stage including me reading out the statements of consent for the resident to verbally respond that they either agreed or disagreed for an audio recording. This particular consent procedure was included with the purpose of being more accessible to care home residents. However the terminology used, as required for the study to receive ethical approval from an ethics committee, seemed to frighten the resident who decided that they would no longer like to take part in the interview. I think that a real issue is present here for researchers where a dissonance exists between what we are required to produce and provide in order to fulfil ethics committee requirements and what is actually appropriate to support recruitment from the target population.

Chapter 5 – A critical discussion of theories of relevance to this thesis

5.1 Chapter overview

This chapter critically discusses theories of relevance to the findings reported in chapters two, three, and four that could inform the development of an intervention undertaken as part of this doctoral thesis. The chapter supports both objectives of this doctoral thesis and has allowed me to gain a deeper understanding of findings and intervention development process through the application of relevant theory.

5.2 Introduction

Previous chapters of this doctoral thesis have highlighted the need for an early intervention to support care home residents to share their research participation wishes and preferences, focusing on addressing challenges surrounding communication. The findings have emphasised the importance of raising awareness, supporting communication, and ensuring relevance and appropriateness in the development of this intervention.

In public health intervention development, theoretical frameworks are used to help guide intervention design and identify the mechanisms through which interventions are able to produce desired outcomes [288]. They provide structured approaches that support the understanding of behavioural influences, ensuring interventions are both relevant and tailored to the needs of a particular target population [289]. A strong focus on theory often enhances the effectiveness of interventions and is associated with better outcomes compared to interventions developed without theoretical foundations [290]. The widely used Medical Research Council's (MRC [82]) guidance framework for complex intervention development and evaluation emphasises the inclusion of theory to support development of interventions, and this will be used in the development stage of the thesis.

In Chapters 2, 3, and 4, I identified theories which can offer explanations for findings. In this chapter, I discuss some of those theories in more depth which I believe are relevant to, and can inform, the intervention development process, including both the strengths and limitations of their application to the current topic.

5.2.1 Chapter aims and objectives

The aim of this chapter is to present and critically analyse relevant theories and, in doing so, identify and select the most appropriate to inform intervention development, in line with the overall aims of this thesis. See Table 5.1 for a summary of relevant theories discussed in this chapter.

5.3 Relevant theories

The relevant theories included in this chapter have been organised under the thematic headings of autonomy, communication, and relationships (Table 5.1). I developed this classification on the basis of how the theories related to main themes from Chapters 2, 3, and 4.

“Collins and Stackton [291] highlight the notion that a balanced use of theory can support qualitative approaches in research. Different applications of theory in qualitative research have been suggested to include theory informing research paradigm and method [292]; data collection influencing theory building [293]; and using theory as a framework to guide a piece of research [294].”

Theory is used in this chapter to interpret the primary findings reported so far in this thesis and is useful in order to contextualise the findings both within the complex care home setting and between relevant systems. Theory can help to explain why particular findings, in certain settings, are apparent, including the mechanisms under which they occur. Further, understanding how theory can explain particular findings may help predict future outcomes and inform likely successes or failures of future intervention development.

Table 5.1 A summary of relevant theories discussed in this chapter

Theory	**Author(s) and date**	**Theory in relation to the current research**	**Strengths of the theory**	**Criticisms of the theory**
Autonomy				
Self Determination Theory (SDT)	Deci and Ryan (1985; 1991; 2000) [214, 215, 263]	Explains that care home residents may become more motivated to share their voice and engage with research if their sense of autonomy is increased	Emphasises the importance of autonomy, competence, and relatedness Has previously been used to develop successful health interventions in a nursing home setting	Application of SDT principles requires personalised interactions with care home residents which may be difficult due to high time and workload pressures
Theory of Learned Helplessness	Seligman (1972) [262]	Explains that individuals may perceive themselves to have no control over their circumstances as a result of repeatedly experiencing uncontrollable events, leading to decreased motivation, emotional distress, and a sense of powerlessness	This can explain the repeated findings of disempowerment shared by residents throughout the literature and our own primary data collection The theory promotes inclusivity Considers the important role of the environment	May imply an oversimplified explanation of behaviour
Communication				
Communication Accommodation Theory (CAT)	Giles 1991 [295]	Suggests that convergence occurs when stakeholders adapt their	Provides insights into the communication dynamics observed in care home settings	May overemphasise the importance of individual

Theory	Author(s) and date	Theory in relation to the current research	Strengths of the theory	Criticisms of the theory
		communication to align more closely with each other, thus improving understanding, whilst divergence occurs when stakeholders maintain their communication style, thus resulting in misunderstanding		adaptation without considering influential systemic factors and policies
Appreciative Inquiry	Cooperrider (1999; 2000) [296, 297]	Explains that inquiry into, and facilitation of, conversations that focus on strengths and potential can drive positive change	Has the potential to enhance engagement by encouraging open communication, collaborative relationships, and a shared vision of success Aligned with person-centred care models and emphasises individuality	Requires a conversation facilitator to align their thoughts and feelings with their questioning style, relying on time, effort, and commitment Risk that changes may be superficial and not supported by deeper structural or behavioural shifts
Relationships				
Social Exchange Theory (SET)	Homans (1958) [298] Thibaut and Kelly (1959) [275, 276]	Explains that human relationships are based on exchanges of resources which can be tangible or intangible, and that people base	SET can explain the identified poor relationships between stakeholders in care home settings	Emphasis placed on rational decision-making

Theory	Author(s) and date	Theory in relation to the current research	Strengths of the theory	Criticisms of the theory
		their engagement on the weight of costs and benefits, aiming to maximise benefits whilst minimising costs	Shares practical methods that can improve effective communication, such as emphasising benefits of taking part in a task	Potentially oversimplifying decision-making in complex environment where emotions are often high and contextual factors play a role
Social Identity Theory (SIT)	Tajfel (2004) [274]	Explains that individuals derive a sense of self-worth and identity from people they categorise themselves with, which influences behaviour	SIT proposes strategies to overcome difficulties in relationships and communication between stakeholders	Focus on intergroup conflict which may overemphasise the negative aspects of group interactions General lack of focus on individual-level factors

5.3.1 Autonomy

5.3.1.1 Self Determination Theory

Self Determination Theory (SDT), developed by Deci and Ryan [263], proposes a psychological framework focusing on human motivation and personality [214, 215, 299]. With three core principles highlighted (autonomy, competence, and relatedness), the theory suggests that people have basic psychological needs that are required to be satisfied in order for optimal functioning and well-being [263].

Autonomy relates to an individual’s need to feel in control of their own actions and decisions [299], and is a concept that has arisen a number of times throughout this thesis. SDT represents an individual’s need to feel effective and capable in their own activities through the competence principle, and refers to relatedness principle as they need to feel connected and valued in relationships [263]. SDT states that these three key principles are essential for promoting intrinsic motivation, which can lead to more engaged and fulfilled individuals [215].

Through findings discussed in previous chapters of this thesis, it is apparent that communication challenges within care home settings often arise due to residents’ perceived lack of autonomy and competence, as well as a lack of relatedness for all stakeholder groups. SDT offers the suggestion that by promoting and increasing care home residents’ perceived sense of autonomy they may become more motivated to share their voice, take part in, and engage with new experiences, such as research. SDT would also propose that improving residents’ sense of being capable when carrying out an activity may make them feel more motivated to take part and engage. This suggests that in the context of the care home setting, tailoring opportunities to residents’ individual needs and abilities could help to promote feelings of competency and thus motivate residents to engage in opportunities presented, such as research participation. Further, the relatedness principle of SDT emphasises the human need to feel connected and valued in order to feel motivated, suggesting that establishing and maintaining good communication and meaningful relationships between stakeholders within the care home setting has the potential to improve residents’ feelings of connectedness and sense of value to others.

The principles of SDT have been used to develop successful health interventions that aim to enhance motivation and engagement in a care home setting. For example, findings of a recent randomised controlled trial in China have shown the effectiveness of a physical activity intervention on depression in care home residents [300]. From their findings, the authors propose that their use of SDT in intervention development may be of relevance to other researchers who are looking for strategies targeting care home settings.

Whilst SDT offers insights into residents' motivation to take part in research, limitations of its application to the goal of this thesis should be considered. Implementing an intervention targeting SDT principles within a care home setting is likely to be hindered by barriers which have been discussed throughout this thesis. For example, high workload and time pressures for staff may prevent personalised interactions with care home residents that are necessary to promote autonomy, competence, and relatedness and thus improve motivation for care home residents. It may also be key to consider that care homes, and their residents, are often constrained by institutional policies and dependency on caregivers, which may make it difficult to apply the principles of SDT [301, 302].

5.3.1.2 Learned Helplessness

Proposed by Seligman in the early 1970's, Learned Helplessness is a psychological phenomenon whereby individuals perceive themselves to have no control over their circumstances as a result of repeatedly experiencing failure or lack of control [262]. This theory suggests that when an individual experiences uncontrollable events repeatedly, they can develop a passive acceptance of their situation leading to decreased motivation, emotional distress, and a sense of powerlessness [262].

The implications of Learned Helplessness may extend to the inclusion of care home residents in research. We know that there are barriers to residents' inclusion, and also reasons why research studies exclude care home residents from studies [52, 58], but it is possible that this exclusion may reinforce a cycle of helplessness because residents may feel marginalised and voiceless in decisions that affect their lives. Further, the Learned Helplessness phenomenon may be relevant when considering care home residents' attitudes towards research participation and their experiences. Through primary data collection during this thesis, I have identified that residents often feel that they lack agency in their lives because of the constraints of their circumstances and the care home environment, and that this impacted their willingness to participate in research. Lending support to this, previous research has indicated that such environments often reinforce feelings of disempowerment, especially when residents perceive that their wishes and choices are overlooked [303].

Learned Helplessness is a concern for care home residents, not only affecting their general motivation but their well-being and quality of life too [265]. By recognising the challenges, and developing strategies to overcome them, researchers may be able to empower residents and ensure that their voices are heard which in turn may encourage a sense of agency and inclusion which can benefit both residents themselves and the research community. Further, it may be possible that Learned Helplessness can itself be addressed through the inclusion of care home residents in research. Researchers may be able to focus on improving residents' perceived autonomy by personally presenting them with opportunities to make choices about their own research participation, facilitating engagement through collaborative working, and providing support to ensure that residents have appropriate resources to understand and contribute to research.

Learned Helplessness provides a strong framework for understanding the impact of feeling powerless and without autonomy. It is effective in explaining the disempowerment identified through the primary data collection undertaken in this thesis, as well as through other published literature, and why residents often feel disengaged or apathetic [150]. Further, the emphasis of Learned Helplessness on the role of environmental factors in shaping behaviour provides a robust explanation of resident behaviour in the context of care homes and helps recognise the impact of institutional settings of feelings of helplessness [211]. Additionally, applying the principles of Learned Helplessness may support the understanding of other systems within the care home setting, for example staff members, for whom a perceived lack of autonomy may be apparent. Staff who consistently experience feeling overworked and under supported may be less likely to engage in extra activities such as facilitating research. Understanding Learned Helplessness in the context of care home settings has the potential to guide interventions aimed at increasing autonomy amongst care home residents and other systems, and thus improve care and quality of life.

Whilst a number of strengths can be seen in the application of Learned Helplessness to understanding care home residents, application of the theory to this particular population is not without its challenges. For example, it has been suggested that the theory provides an oversimplified explanation of human behaviour and motivations [304]. Not all individuals respond to the same stimuli or settings in the same way, and it is likely that other factors such as personality, resilience, and social support play a significant role in how individual care home residents adapt to the care home environment [160]. Further, it is possible that differences in cultures within care home settings play a large role in determining residents' perceptions of helplessness and autonomy [304].

5.3.2 Communication

5.3.2.1 Communication Accommodation Theory

Communication Accommodation Theory (CAT), developed by Giles [295, 305], proposes that people adapt their communication style in order to either converge or diverge from their conversation partner. The role of social identity and group membership is emphasised in CAT, suggesting that people often change elements of their communication style (speech patterns, vocabulary, non-verbal cues etc.) to either enhance mutual understanding or establish social distance [305]. As discussed throughout this thesis, and a target for intervention development, effective communication in care home settings between stakeholders is essential for ensuring the well-being of residents, as well as for sharing opportunities for residents to get involved in research. However, communication challenges between stakeholders are commonly encountered in these settings have been identified.

Applying the convergence and divergence principles to this setting, CAT suggests that convergence occurs when stakeholders adapt their communication to align more closely with each other, thus improving understanding [295]. This suggestion can be supported by previous discussion within this thesis about the potential benefits of tailoring communication styles to residents' needs in facilitating research inclusion.

On the other hand, the divergence principle would suggest that, when certain stakeholders wish to maintain their own communication style, misunderstandings can occur [295]. Again, the divergence principle can be effective to partially explain some findings so far in this thesis, however it seems more likely that stakeholders do not purposefully diverge, but that differences in communication styles are due to unconscious differences in the backgrounds and roles of stakeholder groups.

Understanding the principles of CAT may provide insights into communication dynamics within the care home setting and between stakeholders. The lack of convergence in communication between stakeholders may present a barrier to establishing rapport which, in turn, can prevent research opportunities from reaching residents. Considering this, it may be possible that training could be developed for stakeholders, such as researchers, on how best to communicate and share research opportunities with residents. Additionally, it is possible that intervention resources could be developed to support communication and sharing of wishes and preferences.

The application of CAT offers an effective explanation to residents' engagement in research and to the challenges of doing so. For example, in previous chapters of this thesis I have discussed that when researchers fail to converge their communication styles to the needs of residents, they unconsciously create barriers to inclusion because of misunderstandings. CAT is also valuable in explaining challenges seen in both the literature and from first-hand experience during primary data collection in this thesis. Ethical considerations are essential in research with older adults living in care homes, often referred to as a 'vulnerable' population [202]. However, general ethical guidelines, including the cautious language used within consent forms and participation information sheets, can lead to misunderstanding and thus unintended exclusion [306]. This emphasises a divergence where ethical considerations and protective intentions can result in the exclusion of care home residents as well as reinforcing the disempowerment care home residents often report feeling.

In contrast to the standardised communication of information sheets, CAT places a large focus on how individuals make adjustments to their communication styles and emphasises the importance of individual adaptation [305]. The lack of consideration of systemic factors and policies that may have influence over effective communication in the care home settings therefore could pose a limitation to the application of CAT. Furthermore, sensitivity in adapting communication styles to care home residents has been identified through the available literature and during primary data collection in this thesis. Potential for misunderstandings, as well as causing residents to feel patronised, may arise from using oversimplified language which may also inadvertently undermine dignity and residents’ sense of agency [307]. This is another barrier to engagement and inclusion that has been identified and discussed throughout this thesis.

5.3.2.2 Appreciative Inquiry

Appreciative Inquiry is an approach to change proposed by Cooperrider and Whitney [296, 297]. It is grounded in the belief that inquiry into, and facilitation of conversation about, strengths and potential can drive positive change. One of the core principles of Appreciative Inquiry is a focus on the social construction of reality. Cooperrider and Whitney suggest that positive change is facilitated by emphasis on collective hope and optimism in conversation. It has been suggested that the application of Appreciative Inquiry has the potential to enhance engagement by encouraging open communication, collaborative relationships, and a shared vision of success [308]. There are five principles central to Appreciative Inquiry’s theory-base of change: 1) The Constructionist Principle; 2) The Principle of Simultaneity; 3) The Poetic Principle; 4) The Anticipatory Principle; and 5) The Positive Principle. Briefly, the Constructionist Principle states that ‘knowing’ stands at the centre of every attempt at change [309]. The Principle of Simultaneity recognises that inquiry and change are simultaneous [309]. The Poetic Principle refers to the notion that life is constantly being co-authored and pasts, presents, and futures are “endless sources of learning, inspiration, or interpretation” [309]. The Anticipatory Principle recognises that our collective imagination and discourse about the future is our resource for generating constructive change [309]. Finally, the Positive Principle suggests that building and sustaining motivation for change requires positive emotions and social bonding [309].

Appreciative Inquiry underlies the development of the Caring Conversations (CC) framework [310] which I believe has great potential to work within a care home setting and is discussed in more detail later in the following chapter. The application of Appreciative Inquiry in care home settings has the potential to offer huge benefits related to areas of importance that have been identified from exploring stakeholder views throughout this thesis. Encouraging good relationships, improving communication, and flexibility to residents' needs have all been discussed continuously and pose areas of importance to target in order to improve the inclusion of care home residents in research. Appreciative Inquiry's focus is aligned with person-centred care models and emphasises individuality of each resident. Adapting principles of Appreciative Inquiry to help guide empathetic conversations about research based on residents' needs and abilities can promote a deeper understanding of their research knowledge, wishes, and preferences which in turn may also promote autonomy.

On the other hand, it is important to consider potential limitations of Appreciative Inquiry in the care home setting. Successful application of the five principles requires the conversation facilitator to align their thoughts and feelings with the framing of questions, vocabulary used, and desired outcomes [311]. This may require training for facilitators which will rely upon commitment, time and effort burden for stakeholders for whom we already know these factors are challenging. Further, whilst Appreciative Inquiry has the potential to create a sense of optimism through its positive approach, a risk exists in that changes may be superficial and not supported by deeper structural or behavioural shifts [312]. Relatedly, it is noted that successful application of Appreciative Inquiry principles, leading to sustainable change, relies upon high levels of genuine engagement from stakeholders [313], which may be difficult to achieve in the care home setting context.

5.3.3 Relationships

5.3.3.1 Social Exchange Theory

Social Exchange Theory (SET) was first proposed in the 1950's by Homans [298] discussing "social behaviour as exchange" and further expanded across the social psychology field by other researchers such as Thibault, Kelley, and Blau [275, 276, 314]. SET suggests that human relationships are based on exchanges of resources which can be either tangible or intangible, and that people base their engagement in relationships on the weight of costs and benefits, aiming to maximise benefits whilst minimising costs [275]. Key components of SET include cost-benefit analysis; reciprocity; and trust and relationships. Cost-benefit analysis refers to the idea that people assess perceived costs versus benefits associated with interactions and so positive interactions can encourage cooperation, whilst negative interactions can lead to conflict [275]. The reciprocity component emphasises that social interactions often rely on the expectation of reciprocity, whereby exchanges are appropriate [275]. Further, SET highlights the need for trust within social exchanges and that this can influence the willingness to share information [275].

As discussed throughout this thesis, poor relationships between stakeholders within the care home setting are often reported. SET explains that this could be a result of perceived costs of engagement. For example, due to high workload and time pressures as previously discussed, care home staff may see collaborating with researchers and trying to engage care home residents in research as a burden with little to no personal reward and thus be reluctant to engage. Further, expectations of reciprocity in relationships may offer an explanation to why some stakeholders perceive relationships to be strained in care home settings [315]. For example, should one stakeholder (e.g., the researcher) not be able to offer the same amount of time, flexibility, and resources as other stakeholders, others may become less invested in communicating and engaging effectively. Additionally, if care home residents do not perceive a direct benefit from taking part in research, they may be less likely to take part. Feeling that their contribution to research may be undervalued, or that they will not personally benefit from taking part in research may deter participation. Further, the sensitivity of potential research topics in addition to misunderstandings about research could lead to stakeholders fearing that the emotional costs would outweigh the benefits of engaging in research.

SET can provide useful explanations and help researchers to understanding why care home residents participate in research less that other populations. By considering perceived costs and benefits, reciprocity in relationships, and other potential barriers, researchers may be able to address such concerns. For example, the development of resources to support effective communication emphasising benefits of research participation may be useful, as well as developing practices to reduce perceptions of costs associated with taking part in research.

However, one limitation of SET in relation to care home residents is the emphasis placed on rational decision-making [316]. SET assumes that cost and benefit calculations are rational which, in the specific setting of care homes where emotional factors are often heightened and influencing decision-making, could oversimplify a more complex decision-making process in a population who are often referred to as vulnerable [202]. Similarly, the impact of contextual factors such as institutional policies and practices are overlooked by SET [317], posing another limitation to its application.

5.3.3.2 Social Identity Theory

Social Identity Theory (SIT) emerged in the academic literature in the 1970s, introduced by Tajfel and Turner [318-320], and aims to explain how individuals behave within social groups. The theory emphasises the sense of identity and self-worth people derive from groups they categorise themselves into, which, in turn, influences how they perceive and interact with others [274, 320]. SIT suggests that this categorisation leads to the formation of in- and out-groups, often creating biases that affect communication, relationships, and behaviour [318]. As well as social categorisation, key components of SIT include social identification by which people enhance their self-esteem and sense of belonging by adopting the identity of the group to which they belong; and social comparison by which people compare their perceptions of in- and out-groups which can lead to discrimination [320]. Such group distinctions can result in exclusionary practices in various contexts, including research participation [318].

Again, difficulties in relationships and communication between stakeholders in the care home setting have been highlighted throughout this thesis and SIT offers an explanation as to why these may be prevalent. Identifying with different social groups may create barriers to effective communication. For example, care home staff may identify strongly with their professional group or care home residents may identify strongly with their own social group based on shared experiences, which causes them to distance themselves from perceived out-groups such as researchers. Alternatively, care home staff or relatives may assume they know what is best for residents and make decisions without considering residents' wishes and preferences, as has been documented and discussed in previous chapters of this thesis. Such experiences may lead to residents' autonomy being undermined, feelings of disempowerment, and potentially leading to unwillingness to express their wishes, preferences, or concerns in the future [48, 321].

Further, SIT suggests that in-group members often hold stereotypical views about out-group members [318]. In the context of care home settings, typical stereotypes that residents are less competent due to cognitive impairments, may lead to researchers believing that it is too resource intensive to try to recruit this population, or even that they would not be able to provide reliable data [322]. This reflects a bias rooted in ageism and an overgeneralisation of cognitive decline associated with aging, potentially leading to systemic marginalisation of residents from research [264, 323]. SIT also explains how power dynamics between in- and out-groups may contribute to the exclusion of care home residents in research. Residents may be perceived as having a lower status and less agency compared to other stakeholder groups, such as researchers or care home staff. A perception of residents as passive recipients of care, dependent, or even powerless may reinforce their exclusion from research and overlook their ability to be active contributors to research [324].

One benefit of SIT is the ability to develop strategies to overcome difficulties in relationships between stakeholders and thus communication barriers. SIT offers the suggestion that promoting intergroup contact and collaborative working may be able to mitigate the challenges around relationship building and communication [318]. Research has shown that encouraging positive interactions between in- and out-groups can reduce biases and improve communication [325]. In the care home setting, structured activities where all stakeholder groups engage may be able to facilitate mutual understanding and reduce stereotypes. Furthermore, SIT proposes another strategy whereby a shared identity is developed. When all stakeholder groups can identify as part of a common group, the divide between in- and out-groups can be weakened leading to more collaborative communication [326].

Whilst SIT has a number of strengths, it also is limited in its application to complex, real-world settings, such as care homes, where many stakeholder groups interact. A key limitation of SIT is its focus on intergroup conflict [318], which has the potential to overemphasise the negative aspects of group interactions. It is possible that this focus on conflict might also lead to an oversimplified understanding of the relationships between stakeholders in the care home setting where SIT assumes tension between different stakeholder groups. However, it is apparent that not all interactions and relationships between stakeholders are negative. Collaborative relationships between stakeholders have shown to lead to positive experiences and beneficial outcomes [326], and can be formed through shared activities and common goals. Additionally, the general lack of focus on individual-level factors poses another limitation of SIT. Not all individuals adhere strictly to group identities and often people place more importance on their personal identities than their social identity [327]. SIT fails to consider the role of free-will and offers a more deterministic approach to explaining behaviour [328]. The group-based focus of SIT may therefore offer an obscured view of individualised relationships that are apparent between stakeholders within care home settings.

5.4 Discussion

This chapter discusses theories relevant to the work undertaken in this thesis that could be considered during the intervention development process. By understanding theories which can explain the greatest barriers to inclusion identified, there is a foundation for the development of an intervention to target the communication problem whilst considering the potential influence of perceived autonomy and relationships.

There is overlap between aspects of the theories discussed in this chapter in explaining the identified challenges in communication between stakeholders in care home settings. Particular emphasis is placed the potential benefits of improving care home residents' perceived autonomy in improving motivation to take part in research. This importance is discussed by SDT, the Theory of Learned Helplessness, Appreciative Inquiry, and SIT and highlights the need for the development of an intervention which emphasises the importance of the resident as an individual. It also encourages the consideration of developing an intervention which supports residents to share their research wishes and preferences in a manner that is appropriate and comfortable for them and in which they can feel empowered. Further, emphasis on the importance of relatedness in improving communication between stakeholders is apparent. SDT, Appreciative Inquiry, SET, and SIT all present the need for considering relationships in the development of an intervention which aims to support residents to communicate their wishes and preferences. Therefore, there is a theoretical underpinning for an intervention which foregrounds the importance of facilitating discussions with someone who the resident trusts, has rapport with, and feels comfortable sharing information that they feel to be sensitive. Additionally, it is important to note the potential bi-directional aspect of this work by which having the opportunity to be included in research could itself support the improvement of care home residents' sense of value and perceived sense of autonomy.

Understanding how particular theory helps to explain primary findings in this thesis also offers the potential to contextualise findings in relation to the broader person-centred agenda. For example, emphasis on the importance of relatedness in improving communication between stakeholders and the need for considering relationships in the development of an intervention aiming to support residents to communicate their research participation wishes and preferences, aligns with the wider person-centred care goal of providing respect and being responsive to the preferences, needs, and values of people using a social care service.

5.5 Summary

This thesis chapter has discussed and critically analysed relevant theories identified in previous chapters of this doctoral thesis. In doing so, the intervention development stage of this doctoral thesis can be informed by a deeper understanding of such theories surrounding communication challenges to the inclusion of care home residents in research.

5.6 Reflections

I enjoyed delving deeper into theory for the purpose of this thesis chapter. I think that my background in Psychology (BSc and MSc) helped me to identify and apply relevant theories to my current project and certainly supported the critical analysis within this chapter. Additionally, I have not undertaken intervention development before and so my knowledge regarding the consideration of theory in such frameworks was limited. Undertaking this thesis chapter allowed me to begin applying relevant theory to the next intervention development stage of the project.

Chapter 6 – Review of existing interventions and resources to support decision-making around care and life choices for older adults

6.1 Chapter overview

This chapter presents a brief review of candidate interventions and resources to support decision-making around care and life choices for older adults. Following the previous thesis chapters reporting the collection and interpretation of primary data (Chapters 3 and 4), and relevant theories (Chapter 5), this chapter takes a next step and contributes to the second objective of this thesis by identifying existing interventions and resources which, with the primary data, influence the intervention development stage of this project. Existing interventions and resources are described and discussed in relation to the areas of importance identified by stakeholders. Additionally, an assessment of their suitability for both the original target population and the care home population is discussed, alongside their applicability to this intervention.

Furthermore, the work undertaken in this thesis chapter confirmed that the adaptation of an existing intervention would be the most appropriate approach, following the recommendations of the Medical Research Council's (MRC) guidance for complex intervention development and evaluation [78]. Thus, this chapter also provides the first step of the ADAPT guidance in assessing the rationale for the proposed intervention, and considering intervention-context fit [84].

6.2 Introduction

This doctoral thesis began with an investigation of the barriers and facilitators to the inclusion of older people living in UK care homes (Chapter 2), identified such factors, and developed recommendations for researchers to overcome barriers to inclusion.

Following this, and informed by the review findings, a mixed-methods survey was conducted that explored stakeholders' views about opportunities for older adults living in UK care homes to participate in research (Chapter 3). From the survey an understanding about what stakeholders perceived to be the greatest barriers and facilitators to the inclusion of care home residents in research was gained. Additionally, an understanding of an apparent need to develop strategies to improve communication and relationships between stakeholders, and training programmes to educate stakeholders about care home-based research became apparent.

The next stage of the project was a qualitative interview study exploring stakeholders' views about advance planning for care home residents' research participation (Chapter 4). In agreement with findings from the previous survey study reported in Chapter 3, findings from the interview study highlighted the need to improve communication and relationships between stakeholders, and to ensure all stakeholders have a good understanding about what research entails before residents are recruited. The interviews also provided information about which areas stakeholders deemed to be the most important to target in the development of an intervention to improve the engagement of care home residents in research, with an emphasis on the impact of communication difficulties for this population.

6.2.1 Requirements of the intervention

The previous stages of this thesis have indicated that the following areas should be targeted in order to support communication about research participation wishes and preferences for care home residents: 1) Raising awareness about research; 2) Making the intervention relevant to care home residents; 3) Supporting communication; and 4) Appropriateness of the context.

6.2.1.1 Raising awareness about research

Raising awareness refers to the importance of educating residents about what research might entail and its potential benefits before discussing their research participation wishes and preferences. Additionally, it was considered important to explicitly state the purpose of early discussions about research participation wishes and preferences and what that meant for the resident, now and in the future. Explicit statements about the fact that decisions discussed or documented during these conversations will not cement any future actions or expectations but will be key to raising awareness and assuring stakeholders that they will not be bound to a decision in the future should their wishes, preferences, or needs change.

6.2.1.2 Making the intervention relevant to care home residents

Any intervention should clearly be of relevance to care home residents (e.g., stage of cognitive decline). The intervention should also be both flexible and adaptable to suit the cognitive needs of any individual resident so that they are able to engage with discussion about their research participation wishes and preferences.

6.2.1.3 Supporting communication

The intervention should have the ability to be tailored to each individual resident depending on their communication abilities and accessibility needs. For example, the language used in any provided resources or facilitation of discussions, as well as the format, must be accessible to all residents and potential supporters regardless of health literacy and sensory ability. Above all, the language used, presentation of, and utilisation of the intervention should empower residents to share their wishes and preferences for future research participation.

6.2.1.4 Appropriateness of the context

The conditions under which discussions may take place must be appropriate for, and preferred by, care home residents. This includes the timing of discussions, and how and with whom discussions are carried out. The sensitivity of the topic should also be considered, as well as the delivery formality.

6.2.2 Interventions and resources

Whilst often used interchangeably in the context of health and social care research and various other fields, the terms *intervention* and *resource* have distinct meanings. Firstly, an intervention describes a deliberate and planned action(s) aimed at making a change to a specific behaviour, condition, or outcome [329]. Interventions are often evidence-based considering theories, or models of change, and are evaluated [78]. Depending on the context, interventions can be individual or systemic (e.g., psychological interventions or public health interventions). Interventions require active engagement from participants and their success often depends on the application of chosen strategies within specific contexts [330]. In contrast, a resource refers to something that can be used to facilitate an activity, such as an intervention, but is not itself the primary agent of change [331]. Resources may be tangible or intangible and can include tools, materials, people, or knowledge that supports the implementation of an activity. Resources are often the means through which interventions are made possible, and their availability can influence the success of, or propose a barrier to, an intervention. This is seen consistently in many settings, including healthcare [332] and education [333].

6.2.3 Review purpose and aims

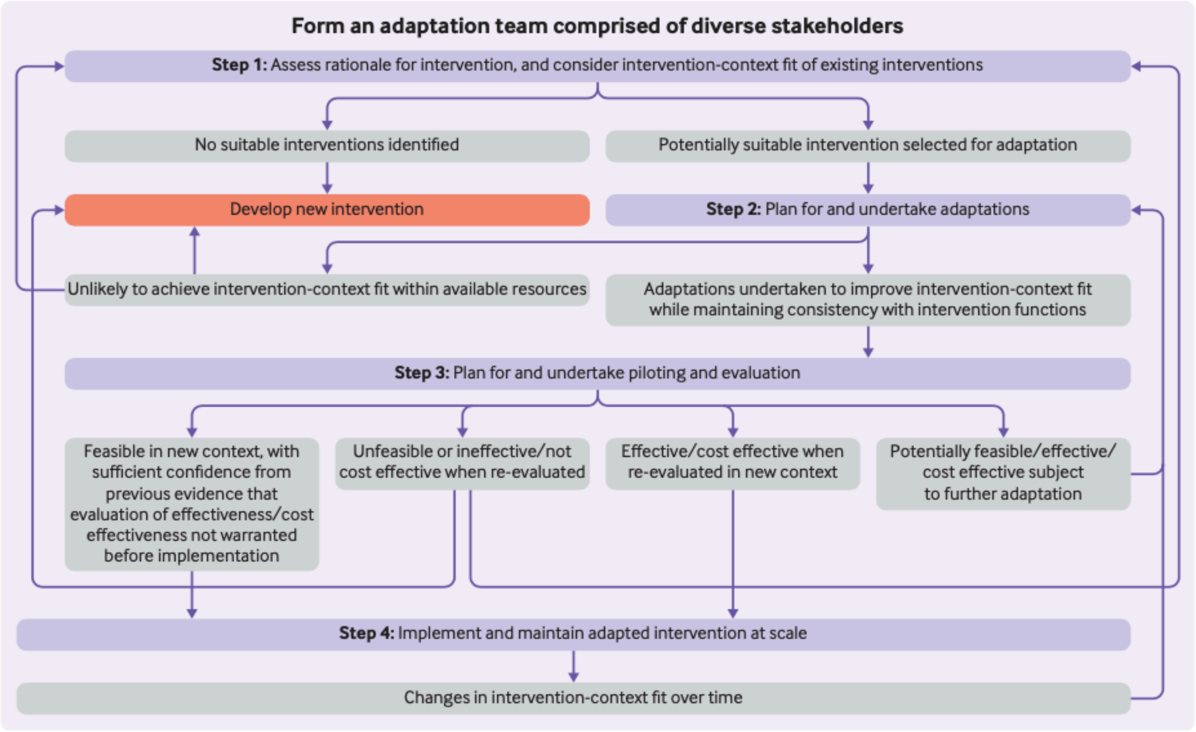
The aim of this review was to identify any relevant existing interventions and resources that have been developed, and exist, to support decision-making around care and life choices for older adults.

This thesis chapter discusses the findings of a search of existing interventions and resources that aim to support older adults to share their wishes and preferences about future care and life choices. Reviewing published evidence during the development of complex interventions is suggested by the MRC [78] as a step in their proposed ADAPT guidance for intervention adaptation [84]. This latest guidance discusses the importance of considering any overlapping features between the intended intervention and existing interventions because this may suggest intervention adaptation is the most appropriate and beneficial route [78]. Reviewing existing research evidence allows researchers to identify and understand what has already been done within the field, identify gaps, and build on existing knowledge [334]. Additionally, in completing a review of existing research evidence, researchers can avoid duplication of work, identify best practices, and ensure that their own intervention development is evidence-based [78]. By synthesising existing work, researchers can be guided by a systematic approach that has the potential to enhance the likelihood of success for the development and implementation of new interventions [335, 336].

6.3 Methods

As stated above, this chapter presents and discusses findings fulfilling Step 1 of the ADAPT guidance [84]. The ADAPT process model can be seen in Figure 6.1.

Figure 6.1 The ADAPT process model for adapting interventions to new contexts



Purple boxes=stages of ADAPT step-by-step guidance. Grey boxes=potential outcomes from each stage. Directional arrows=recommendations for moving, forward, or backwards through stages (or exiting) [84].

6.3.1 Design

A search was conducted in MEDLINE, in March 2024. The search strategy included Population, Intervention, and Outcome elements, as well as limits placed on language and dates to ensure manageable results (Table 6.1). Articles were exported to Endnote, a reference management software, and their titles and abstracts were screened. As this is a novel area for an intervention, articles were included if they mentioned the development, or use, of an intervention to support decision-making about care or life choices for older adults in the title or abstract. Additionally, further online searches were conducted to identify any existing interventions and resources that may not have been part of published studies or development processes. These searches included web pages of relevant networks and Google searches from which six further interventions and/or resources were identified.

Table 6.1 Search strategy

Population		Older adult* **OR** Older person* **OR** Elder*
Intervention	AND	Tool* **OR** Aid* **OR** Interven* AND Support* **OR** Help* **OR** Assist* AND Decision* **OR** Decid* **OR** Wish* **OR** Prefer* AND Develop*
Outcome	AND	Communicat* **OR** Express* **OR** Shar*

	AND	Limit: English Language 2010 – current

6.3.2 Data extraction and reporting

The purpose and aim(s), target population, and type of intervention or resource were extracted, as well as the format of each including delivery and any resources required (see Tables 6.2 and 6.3). In addition information regarding any theories underpinning the development of interventions and resources were reported. Where information of interest was not readily published, article authors were emailed to request it.

The elements of each intervention and resource were then considered in relation to the identified areas of importance from the ENGAGE project study findings (Section 6.2.1). These was considered for both the target population of the existing interventions and resources, and the adaptability of these for the care home population. Additionally, any available relevant research focusing on intervention and resource feasibility and acceptability is reported and discussed.

6.4 Results

321 articles were identified through the online database search, and six from other sources (Figure 6.2). Following article exclusion 12 articles discussing existing interventions and resources were included in this thesis chapter. Table 6.4 reports the included existing intervention properties mapped against the four suggested requirements from stakeholders for their Target Population (TP) and if they would fulfil suggested requirements for Care Home Residents.

Figure 6.2 PRISMA flow diagram showing the identification of articles (PRISMA, [337]).

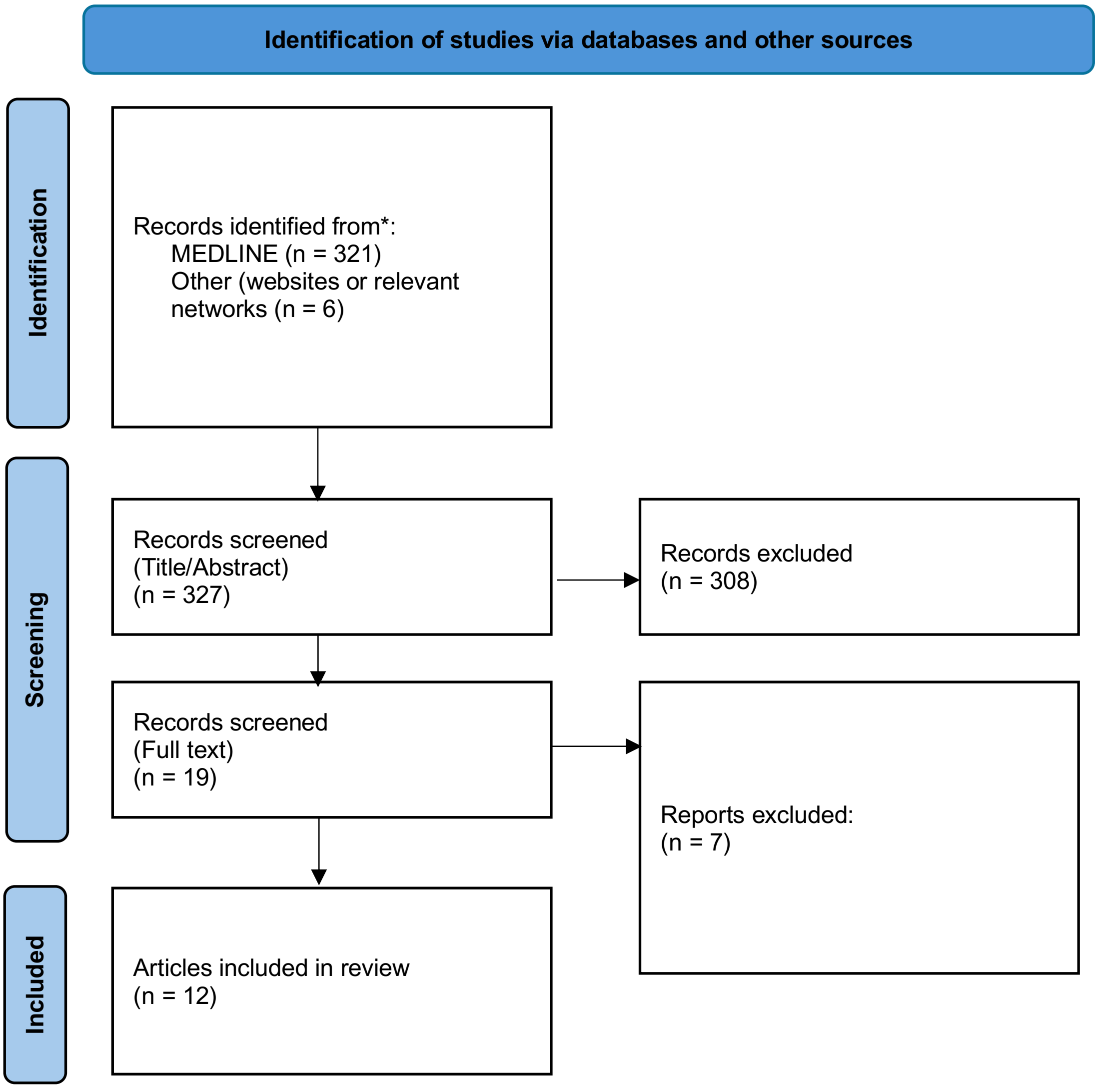


Table 6.2 Characteristics of included existing interventions (see next page)

Name of intervention (Author, Date)	**Intended target population**	**Aim(s)**	**Underpinning theory/theories**	**Type of intervention**	**Format of intervention and delivery**
Caring Conversations, Dewar and Nolan, 2013 [310]	Older people in a care setting	To implement compassionate relationship-centred care in an older people setting	Appreciative inquiry: The Constructionist Principle The Principle of Simultaneity The Poetic Principle The Anticipatory Principle The Positive Principle	Appreciative inquiry combined with action research	Evidence-based set of questions about having caring conversations

Name of intervention (Author, Date)	Intended target population	Aim(s)	Underpinning theory/theories	Type of intervention	Format of intervention and delivery
CHAT&PLAN, Corbett et al., 2020 [338]	Older people living with multimorbidity	To promote person-centred care and support self-management for older people living with multimorbidity	Burden of Treatment Theory Shippee's cumulative complexity model Cognitive Authority Theory Self-Determination Theory Participative Goal Setting	Structured conversation-based intervention	Resource sheet with conversations to go through and lots of details about how to initiate and maintain conversations

Name of intervention (Author, Date)	Intended target population	Aim(s)	Underpinning theory/theories	Type of intervention	Format of intervention and delivery
			Gollwitzer's concept of implementation intentions		
Deciding Together, Tay er al., 2020 [339]	Older adult home health patients and caregivers	To improve decisional quality, readiness, collaboration, and concordance in advance care planning discussions	Dyadic Coping theory Developmental-contextual model The theory of multiple goals of communication (Van Scoy et al. 2016)	Theory-based advance care planning intervention	The intervention consists of: A clinical vignette, Theoretically guided conversation prompts, and a shared decision-making activity

Name of intervention (Author, Date)	Intended target population	Aim(s)	Underpinning theory/theories	Type of intervention	Format of intervention and delivery
			Shared decision-making, grounded in the social constructionism epistemological perspective		
Let's Talk Tech, Berridge et al., 2022 [340]	People living with Alzheimer's Disease and their family care partner	To improve care partners' knowledge of the technology preferences of the person living with dementia and related values to prepare them to make the best decisions in the future should the person lose capacity to consent.	Theory of Dyadic Illness Management	Self-administered web application	Completed by person with early-stage Alzheimer's Disease together with their primary care giver in a collaborative process Includes: - Education - Discussion questions

Name of intervention (Author, Date)	Intended target population	Aim(s)	Underpinning theory/theories	Type of intervention	Format of intervention and delivery
		To facilitate communication and sharing of preferences. To meaningfully engage people living with mind dementia in planning for the use of technology in their safety and care, and to enable understanding of the implications of technology use and communication about it, so families are not left to navigate this complex space alone.			- Documentation of preferences expressed by the person living with dementia Requires: - Person with dementia - Primary care giver - Internet-connected device

Table 6.3 Characteristics of included existing resources

Name of Resource (Author, Date)	Intended target population	Aim(s)	Underpinning theory/theories	Type of resource	Format of resource and delivery
Advance Care Planning (ACP) Medizinisch Bagleitet decision aids, Bosisio et al., 2021 [341]	People living with early dementia	A dementia specific advance care planning tool, developed in Switzerland. To support autonomy of people with early dementia, increase the frequency and quality of advance directives, and improve relative's knowledge of the preferences of the person with early dementia.	The Conflict Model of Decision Making Theory of Planned Behaviour Self-Determination Theory	Structured interview including dementia-specific scenarios	Structured interview Action-centred tool emphasising shared decision-making about goals of care
Fink Cards, Sanderson et al., date [342]	Any persons wishing to engage in conversations	To help start and guide people to share: What matters to you now and at the end of your life How you like to talk about things	Person-centred practice principles influence by	Tool to guide people to have conversations about advance care planning	Physical conversation cards ACP example: 48 questions to help you share:

Name of Resource (Author, Date)	**Intended target population**	**Aim(s)**	**Underpinning theory/theories**	**Type of resource**	**Format of resource and delivery**
	about advance care planning	What decisions or choices are important to you	underpinning theories: The Person Centred Counselling and Therapeutic Model Self-Determination Theory Smale's work: The Procedural, The Questioning, and The		What matters to you now and at the end of your life How you like to talk about things What decisions or choices are important to you

Name of Resource (Author, Date)	Intended target population	Aim(s)	Underpinning theory/theories	Type of resource	Format of resource and delivery
			Exchange Models The Citizenship Model		
Go Wish, Coda Alliance, 2022 [343] **Swedish version – DöBra**	Low-functioning assisted-living facility residents, their family members, and their CAN/nursing assistants	To help people discuss end-of-life care	Emailed	Advance care planning tool	Go Wish Card Game The tool can be used by staff or even a caregiver after minimal instruction Professionally designed and printed cards that are boxed as a game set

Name of Resource (Author, Date)	Intended target population	Aim(s)	Underpinning theory/theories	Type of resource	Format of resource and delivery
My Life, My Wishes, Powys Teaching Health Board NHS [344]	Adults (18+) who have mental capacity	To help adults record their wishes about how they would like to be cared for in the future	Emailed	Document that stays with the user to complete an advance care plan or statement of wishes	Document and guidance booklet
My Wellbeing Journal, Lawless et al., 2024 [345]	Older adults with chronic conditions and multimorbidity	To improve care for older adults with chronic conditions and multimorbidity	Shared Decision Making Person-Centred Care Collaborative goal setting	Communication and goal-setting tool	A5 booklet divided into four sections: 1. Exploring what matters 2. Doing what matters 3. Discussing what matters 4. Journal entries

Name of Resource (Author, Date)	**Intended target population**	**Aim(s)**	**Underpinning theory/theories**	**Type of resource**	**Format of resource and delivery**
Photo Story Booklet, Koops van't Jagt et al., 2019 [346]	Older adults with limited health literacy	To support older adults with limited health literacy when communicating during their primary care consultations	Narrative Theory Social learning theory Health behaviour theories The salient belief elicitation The theory of planned behaviour	Photo stories to support doctor-patient communication	Seven photo stories developed incorporating principles from narrative and social learning theory and covering communication themes and strategies identified during focus group discussions and role-play exercises. The intervention was developed in 3 different formats: 1-page photo stories, narrated video clips using the original photo story pictures and interactive video clips covering participation and communication during primary care consultations

Name of Resource (Author, Date)	Intended target population	Aim(s)	Underpinning theory/theories	Type of resource	Format of resource and delivery
			The health action process Stages of change in behaviour		
Talking Mats – Thinking Ahead, Murphy, 2013 [347]	People with communication difficulties	To support comprehension and improve quality of conversation	Emailed	Visual communication framework which supports people with communication difficulties to express their feelings and views	Physical card resource or digital talking mats

Name of Resource (Author, Date)	**Intended target population**	**Aim(s)**	**Underpinning theory/theories**	**Type of resource**	**Format of resource and delivery**
Your Life, Your Choices, Pearlman, 2010 [348]	Anyone	To support people to plan for future medical decisions and prepare a personalised will	Stages of Change in behaviour The Health Belief Model Self-efficacy	Information workbook on advance care planning	Workbook Part 1 – The Basics Part 2 - Resources

Table 6.4 Candidate intervention and resource properties

Candidate interventions and resources	**Suggested requirements**							
	Raising awareness		**Making it relevant**		**Supporting Communication**		**Appropriateness**	
	TP	CHR	TP	CHR	TP	CHR	TP	CHR
ACP Medizinisch Bagleitet decision aids	No	No	Yes	Yes	Yes	Yes	No	No
Caring Conversations	No	No	Yes	Yes	Yes	Yes	Yes	Yes
CHAT&PLAN	No	No	Yes	No	Yes	No	Yes	No

Deciding Together	No	No	Yes	Yes	Yes	No	Yes	No
Fink Cards	No	No	Yes	Yes	Yes	Yes	Yes	Yes
Go Wish	No	No	Yes	Yes	Yes	Yes	Yes	Yes
Let’s Talk Tech	Yes	Yes	Yes	No	Yes	No	No	No
My Life, My Wishes	Yes	Yes	Yes	No	Yes	No	Yes	No
My Wellbeing Journal	Yes	Yes	Yes	No	Yes	No	Yes	No
Photo Story Booklet	No	No	Yes	Yes	Yes	Yes	Yes	Yes
Talking Mats	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Your Life, Your Choices	Yes	Yes	Yes	No	Yes	No	Yes	No

Candidate intervention and resources mapped against the suggested intervention requirements from stakeholders in the ENGAGE study for their respective Target Populations (TP) and if they could fulfil suggested requirements for Care Home Residents (CHR) if adapted for research.

6.4.1 Existing interventions

This section reports a description of the characteristics and theories underpinning included interventions. The elements of each are also discussed in relation to the four identified areas of importance from the ENGAGE project study findings so far, considered for both the target population of the existing interventions and the adaptability of these for the care home population (see Table 6.4). Additionally, any available relevant research focusing on existing intervention feasibility and acceptability is reported and discussed. The assessment of suitability for the existing interventions' target populations and the care home population is based on my judgement and knowledge of the care home setting and population, and is evidence based, where the evidence exists.

CHAT&PLAN

CHAT&PLAN is a structured conversation-based intervention, developed by Corbett et al. [338] aiming to facilitate person-centred care, support self-management, and improve quality of life for older people living with multimorbidity (see Appendix 6.1). The intervention consists of a resource sheet with designated conversations to work through and includes details about how to initiate and maintain conversations. The intervention requires the user to be knowledgeable about their conditions and related needs and facilitates relevant person-centred discussion about these. The questions included support focused communication for the user and aims to support self-management.

Theories underpinning the development of the CHAT&PLAN intervention focus largely on patient workload and include Burden of Treatment Theory [349]; the Cumulative Complexity Model [350]; Cognitive Authority Theory [351]; and Self Determination Theory (SDT [352]). Burden of Treatment Theory represents the relationship between capacity for action and the work passed on to patients and their relational networks by healthcare systems [349]. The Cumulative Complexity Model [350] aims to explore how individual level confounding factors may accumulate due to multimorbidity and how poor outcomes are likely to be derived from an imbalance between patient workload of demands and patient capacity. Informed by social epistemology, Cognitive Authority Theory outlines negotiation processes in which people manage important relational aspects of inequalities in power and expertise, particularly relating to the management of long-term conditions [351]. SDT [352] proposes a theory of motivation, explaining that in order to achieve autonomy, patients seek supportive relationships in which their emotions and beliefs are respected.

Due to the format of delivery and goal-setting nature of CHAT&PLAN, the intervention may not be most appropriate for facilitating discussion with care home residents about their possible future incapacity, and their wishes and preferences for research participation. A more personable, sensitive approach may be warranted.

Caring Conversations

Developed by Dewar and Nolan [310], Caring Conversations (CC) is a framework created to implement compassionate relationship centred care in an older people setting (see Appendix 6.2). The intervention framework comprises of an evidence-based set of questions that encourage discussion and promote caring conversations in a collaborative manner. The question set also allows the chance for the user to be reflective.

The framework, also known as 'The 7 C's', takes into consideration necessary factors required to promote caring conversations that are: **C**ourageous, **C**onnect emotionally, **C**urious, **C**onsider other perspectives, **C**ollaborate, **C**ompromise, and **C**elebrate.

Underpinning the development of the framework is Appreciative Inquiry [297] utilising the four principles of Appreciative Inquiry which state that inquiry appreciative, applicable, provocative, and collaborative. There are five principles central to Appreciative Inquiry's theory-base of change: 1) The Constructionist Principle; 2) The Principle of Simultaneity; 3) The Poetic Principle; 4) The Anticipatory Principle; and 5) The Positive Principle. Briefly, the Constructionist Principle states that 'knowing' stands at the centre of every attempt at change. The Principle of Simultaneity recognises that inquiry and change are simultaneous. The Poetic Principle refers to the notion that life is constantly being co-authored and pasts, presents, and futures are “endless sources of learning, inspiration, or interpretation.”, acknowledging that there is not a single topic that we cannot study. The Anticipatory Principle recognises that our collective imagination and discourse about the future is our resource for generating constructive change. Finally, the Positive Principle presents, from experience, that building and sustaining motivation for change requires large positive affect and social bonding.

In a study utilising the framework, Dewar and Nolan [310] were able to demonstrate that engaging in appreciative caring conversations promotes compassionate, relationship-centred care but that these conversations involved practitioners taking risks. Such relational practices must therefore be valued and accorded status. Staff require appropriate support, facilitation and strong leadership if these practices are to flourish.

Further, evidence suggests that the framework has relevance to the care home setting and the development of an educational intervention to enhance the development of human interaction [353]. The study concluded that CC are crucial to developing relationships within care home settings, helping to promote a dignified and compassionate experience for all. The CC framework may therefore be appropriate to incorporate in the development of an intervention to support the sharing of wishes and preference for research participation by care home residents.

The CC framework considers the sensitivity of the topic of conversation and promotes empowerment for those taking part in a discussion. It’s flexibility and adaptability, coupled with an emphasis on taking a caring approach to discussion, makes it relevant to older adults as well as supporting meaningful conversation.

Deciding Together

Deciding Together (DT) is a collaborative ACP intervention for older adult home health patients and their caregivers developed by Tay et al. [339]. The intervention aims to improve decisional quality, readiness, collaboration, and concordance in advance care planning discussions using a theory-based process. DT consists of a clinical vignette, theoretically guided conversation prompts, and a shared decision-making activity (see Appendix 6.3). The process allows patient-caregiver dyads to reflect on past and present medical decision-making and examine how medical decisions have shared consequences. The vignette presented includes a 'stressor' (i.e., a challenging situation) from which dyads are encouraged to think about and discuss consequences for the other person who has to decide about continuing or withdrawing life-sustaining treatments. Open sharing and active listening techniques are encouraged.

Development of the DT intervention was focused around shared-decision-making and grounded in the social constructionism epistemological perspective [354]. This perspective suggests that one's interaction with both societal norms and with other people shape reality and meaning in our lives. For example, the Developmental-Contextual Model, which suggests that a dyads' response to a shared stressor is influenced by developmental and sociocultural characteristics and through processes of both individual and dyadic appraisals, lead to coping strategies which are either adaptive or maladaptive [355]. Consistent with the constructs of the model, the development of the DT intervention identified the processes of dyadic appraisals and positive dyadic coping strategies as integral to promoting a shared mind for advance care planning.

An evaluation study of this collaborative advance care planning intervention [339] suggested that collaborative advance care planning decision-making may improve decisional conflict for older adult home health patients and their caregivers. However, no significant differences were found for perceptions of collaboration, and readiness for advance care planning.

The DT intervention is able to ensure relevance for its users through adaptability via inclusion of a user's own experiences. Although there is no education section to raise awareness of the topic of interest, the use of vignettes may support to users for whom more formal delivery is unfavourable. However, the ultimate goal of reflecting on past and present medical decisions, as well as the consequences of such decisions, may not necessarily promote empowerment and guidance for future goal planning.

Whilst the tasks used by this intervention may be appropriate for older adult home health patients and their carers, it is likely that those residing in a care home have additional needs that need to be met through the ability of an intervention to be flexible and adaptable, considerate of topic sensitivity, and more supportive of communication for individuals considering their abilities.

Let's Talk Tech

Developed by Berridge et al., [340, 356] Let's Talk Tech (LTT) is a self-administered web application for people living with Alzheimer's disease and their family care partners. The intervention focus is on advance planning for technology use in dementia care. LTT has a number of aims, including making care partners aware of the person with living with dementia and other related values to prepare them to make decisions in the future should the person lose capacity to consent; facilitate communication and sharing of preferences; and to engage the person living with dementia in planning for the use of technology in their safety and care.

LTT is completed by a person with early-stage Alzheimer's disease together with their primary care giver in a collaborative process. The process includes education, discussion questions, and documentation of preferences expressed by the person living with dementia. The intervention requires a person with dementia, their primary caregiver, and access to an internet-connected device. After the modules are completed, participants are guided through relevant questions in order to state options that are important to them. The web application provides a summary document of their choices and discussion.

Development of the LTT intervention was informed by the Theory of Dyadic Illness Management, which posits that care dyads with shared understanding of each other’s perceptions and values, and illness progression (i.e., appraisals), and more collaborative illness management, have better health outcomes [357].

Results from an efficacy study conducted by Berridge et al. [356] showed a significant improvement of care partners’ understanding of each technology, care partners’ perceptions of the understanding of each technology by the person living with dementia, knowledge of the preferences of the person living with dementia, decision-making preparedness, and care partners’ feelings of mutual understanding. Participants in the efficacy study reported that LTT helped them have meaningful and important conversations about using technology in order to help with their personal safety.

Whilst informative and useful for some people with early dementia, the approach LTT utilises may not be the most appropriate for care home residents in supporting communication on a topic. The online format is unfavourable for older people living in care homes, as stated by stakeholders, due to accessibility challenges. Further, whilst the intervention topic promotes future independence, the sensitivity of such discussions needs to be considered and the intervention adaptable in turn.

6.4.2 Candidate resources

This section reports a description of the characteristics and theories underpinning the resources being reviewed. As above, the elements of each are also discussed in relation to the four identified areas of importance from the ENGAGE project study findings so far, considered for both the target population of the existing interventions and the adaptability of these for the care home population (see Table 6.4). Additionally, any available relevant research focusing on existing intervention feasibility and acceptability is reported and discussed. The assessment of suitability for the existing resources’ target populations and the care home population is based on my judgement and knowledge of the care home setting and population, and is evidence based, where the evidence exists.

ACP Medizinisch Begleitet decision aids

Bosisio and colleagues [341] developed a dementia-specific ACP tool based on the existing Medizinisch Begleitet tool [358]. This resource aims to support the autonomy of People with Early Dementia (PWED), increase the frequency and quality of advance directives, and improve relatives' knowledge of the care preferences of the person with early dementia. Decision aids from the existing tool were simplified to make them easier to read and understand for those with early dementia. Through the use of structured interviews, this action-centred tool emphasises shared decision-making about goals of care. See Appendix 6.4 for relevant resources.

The intervention consists of two parts: Part 1 requires trained facilitators to engage people in a structured discussion about life and death, quality of life, and past experiences with care; Part 2 encourages the PWED to appoint a surrogate decision-maker and document advance directives in three distinct situations of lost decision-making capacity (sudden loss due to emergency, loss for an uncertain period of time, permanent loss). In each scenario, people are asked to choose a goal of care (prolong life; prolong life with treatment limitations; or comfort only care).

The development of decision aids have been underpinned by theories aiming to explain how people make decisions under risk and uncertainty, and the factors influencing our judgements and choices [359], such as the Conflict Model of Decision Making [360]. This model highlights the complexity of decision-making and suggests that performing this act includes the weighing of conflicting motivations or values [361]. In addition, the Theory of Planned Behaviour (TPB; [362]) suggests that intentions related to behaviour are developed depending on individuals' attitudes, perceived control, and subjective norms. SDT [352] posits that behavioural motivation is developed through the attainment of different psychological needs, such as autonomy.

The ACP Medizinisch Begleitet intervention's adapted decision aids to ensure relevance and suitability for the targeted population of those with early dementia. The structured decision-making requirements about life and death, quality of life, and past experiences means that it is focused and relevant to the user. The intervention seems to be tailored more towards improving relative's awareness of wishes and preferences regarding future care planning, rather than empowering the user and supporting communication about a potentially sensitive topic. The use of specific scenarios may lessen the adaptability of the intervention to the user, however decision aids ensure that the means of communication are appropriate for PWED.

The results of a pilot trial by Bosisio et al. [341] suggest that this intervention is favourable for their targeted population. Both PWED and their relatives expressed satisfaction with the procedure, especially regarding the opportunity to discuss a sensitive topic with the help of a facilitator. However, a number of feasibility challenges were observed including: locating eligible patients; tailoring recruitment procedures to recruitment locations; adapting inclusion criteria to clinical routes; engaging PWED and their relatives in ACP; and designing a trial that does not burden PWED. Bosisio and colleagues note the insight that despite the challenges, the intervention increased the number of advance directives, the concordance between PWEDs preferences and relatives' decision on their behalf, and relatives' perceived control over healthcare decisions.

The structured interview format used by this intervention may be too formal and intimidating to care home residents who need to be supported to communicate their wishes and preferences about a potentially sensitive topic.

Fink Cards (Advance Care Planning set)

Fink Cards are a communication tool that can be used to facilitate conversations about a number of topics. The Advance Care Planning set (see Appendix. 6.5), written by Sanderson and Russell, help users engage in discussions about planning for the end of life. The cards include 48 questions to help start and guide people to share: 'What matters to you now and at the end of your life'; 'How you like to talk about things'; 'What decisions or choices are important to you'. The cards are suitable for health and social care professionals wishing to use an evidence-based advance care planning, person-centred resource.

Listening, Sharing Power, Responsive Action, and Connecting with Citizenship are the principles of Person-Centred Practice which underpins the development of the Fink Cards resource. The foundation of the Listening principle lies within the Person-Centred Counselling and Therapeutic Model [363]; SDT [352] underpins the importance of the Sharing Power principle; the Exchange Model, featured in Smale's work [364] offers explanation to Responsive Action; and informed by the work of the Inclusion Movement, the Citizen Model [365] offers an understanding of the importance of connecting with citizenship. In relation to the Connected with citizenship principle, Duffy (2003), informed by the work of the Inclusion Movement, proposes six 'keys' that collectively enable individuals to achieve full citizenship: 1) Self-determination; 2) Money; 3) Direction; 4) Home; 5) Support; and 6) Community Life.

The Fink Cards resource requires users to already possess knowledge of the topic under discussion. The number of questions offered make it relevant to its users and suitable to all who wish to initiate and maintain discussion about a topic with a Health and Social Care Professional. Fink Cards offer the ability to tailor conversation to the needs of the user and, as a physical card resource with specific discussion topics, support communication.

The features of the Fink Cards resource may be beneficial to the development of a communication intervention to support care home residents. The less formal nature of the intervention is another attractive quality for use with care home residents who may find more formal processes intimidating and thus hinder discussion about sensitive topics.

Go Wish

Developed by Coda Alliance, Go Wish is an ACP tool for end-of-life care conversations [366]. It is a card game which was developed to help low-functioning assisted-living facility residents, their family members, and nursing assistants to have discussions about end-of-life care (see Appendix 6.6). The cards focus conversations and provide useful vocabulary to support patients to share their needs and concerns, offering a means for sharing those ideas. Questions can be answered with 39 single-value or goal cards, as well as a wild card to keep options open-ended. The cards are introduced as some examples of what people might say is important to them if nearing end-of-life.

Similarly to the other included interventions that provide physical resources, such as cards, the Go Wish intervention is able to initiate, maintain, and support communication for users. The Go Wish intervention is flexible and appropriate for those wishing to have end-of-life care conversations who are likely to require adaptations to resources such as large, easy-to-read text. Whilst not inclusive of educating resources around end-of-life care to begin with, the Go Wish intervention includes real-world examples of how other people may answer the questions included as well as a ‘wild card’ which empowers users to share alternative perspectives. The ability to utilise the Go Wish intervention with minimal instruction allows users to consider the influence of relationships between users and the formality under which the resource is used, and the offering of important vocabulary for users is empowering and supportive of communication.

Through a series of case studies presented in a paper by Menkin [366], it appears that the Go Wish cards are able to promote, and benefit, conversations between patients, loved ones, and medical care providers. The cards are able to be used by all after minimal instruction and provide a useful, inexpensive, and intuitive tool for furthering goals and value-oriented conversations about illness and preferences for care, for facilitating patient-proxy-provider understanding, and for identifying hopes. Framing the discussions around “These are some things people have said are important to them. Which might be important to you?” seems an effective way to initiate and maintain conversation.

The qualities discussed seem to satisfy what stakeholders have deemed important in developing an intervention for care home residents to share their wishes and preferences about research participation. The features of a physical resource may be appropriate to consider in the development of a communication intervention to support care home residents to share their wishes and preferences about research participation.

My Life, My Wishes

The My Life, My Wishes document was developed by a working group within Powys Teaching Health Board's Specialist Palliative Care Team (see Appendix 6.7). Officially launched in 2019, two further updated versions have since been released. My Life, My Wishes advanced care planning resource helps adults with mental capacity to record their wishes about how they would like to be cared for in the future. It comprises of a document and guidance booklet, which stay with the user to complete at any time. The user does not have to be unwell to use it and it can be completed by the user alone or with support.

The document consists of six sections: 1) My Details; 2) Thinking Ahead – My Values and Beliefs and My Health; 3) My Future – Specific Wishes; 4) My Last Days; 5) After My Death-; 6) Information to help Health and Care Professionals. All of which get the user thinking about elements of advance care planning. In addition to these sections are additional spaces for updates. The guidance booklet resource contains information to educate the user on all topics that are mentioned in the document. This includes information about advance care planning; mental capacity; best interest; advance decision to refuse treatment; lasting power of attorney; DNACPR; last will and testaments; organ and tissue donation; and useful contacts and information.

The My Life, My Wishes intervention provides a guidance document that raises awareness and educates users about the topic of advance care planning. The intervention can be undertaken alone or with support and is relevant for anyone who has mental capacity. According to the NHS Wales Powys Teaching Health Board website, there has been widespread uptake of My Life, My Wishes within Powys, including within the Health Board, County council, Third Sector, and local people, and overall the document has been successful.

My Life, My Wishes promotes independence and flexibility for users but, due to the resource’s largely one-size-fits-all approach, it may not be suitable for care home residents who may require more guidance and support to facilitate conversations on potentially sensitive topics. For these reasons, and also the inability to adapt to individuals’ unique accessibility needs, the My Life, My Wishes intervention may not be the most appropriate approach for care home residents to share their wishes and preferences about research participation.

My Wellbeing Journal

My Wellbeing Journal is a communication and goal-setting tool, developed by Lawless et al. [345], aiming to improve care for older adults with chronic conditions and multimorbidity (see Appendix 6.8). The intervention consists of a booklet resource which is divided into four sections: 1) Exploring what matters; 2) Doing what matters; 3) Discussing what matters; 4) Journal entries.

The first section, ‘Exploring what matters’, introduces the concept of goal setting and the various aspects of health and wellbeing that can affect individuals’ goals. The second section, ‘Doing what matters’, provides further information about goal setting and tips for setting achievable goals. ‘Discussing what matters’, section three, emphasises the importance of good communication between patients and their healthcare team and provides a list of prompt questions. The final section, ‘Journal entries’, provides a space for users (with or without assistance) to record their overall quality of life, sources of stress, questions for their healthcare team, goals, and reflect on their progress. Goal setting has been identified as a priority in policies and guidelines for specific long-term conditions, multimorbidity, and frailty [34], and is central to the theory and effective practice of care planning [3].

In an article reporting final end-user feedback [345], it was apparent that older adult participants found the contents of the journal to be informative and relevant. Participants also fed back that the format of the journal was simple and convenient and that the design was appealing and appropriate. However, negative feedback from participants included comments relating to some of the language used in the journal not being accessible to the target audience of older people and their carers, but more academic.

Like the other included interventions that provide a document or similar resource, My Wellbeing Journal is relevant for users who are more independent and able to complete the written communication resource with minimal support. The inclusion of all relevant information to educate users on the topic promotes independent use, and the section format ensures coverage of topics which can be tailored to the user, by the user.

In terms of the adaptability and flexibility of use for care home residents, My Wellbeing Journal may be more appropriate for those without additional needs and who require support in communicating their opinions, wishes or preferences on a topic. The written format may not be accessible to all care home residents, and the largely independent nature of the intervention may be less appropriate for care home residents who may need more support navigating a topic.

Photo Story Booklet

The photo story booklet, a communication intervention for older adults with limited health literacy, was developed by Koops van't Jagt et al. [346] and aims to support doctor-patient communication during primary care consultations (see Appendix 6.9). The booklet includes seven photo stories which were developed by incorporating principles from narrative and SLT, and covering communication themes and strategies identified during focus group discussions and role-play exercises. The intervention has been developed into three different formats: 1) one-page photo stories; 2) narrated video clips using the original photo story pictures; and 3) interactive video clips covering participation and communication during primary care consultations.

Theories underpinning the development of the photo story booklet resource include theories of narrative mechanisms and theories of social and observational learning. For example, Schank and Abelson [367] posit that virtually all of the important social knowledge is composed of stories that people either construct from their own life experience or learn from other sources. Theories of social and observational learning are grounded in Social Learning Theory which states that observation and imitation of others' behaviour results in learning [220], hence the photos used in the booklet portraying typical behaviours in the setting for those with limited health literacy to consider and base their own behaviours on.

In a study by Koops van't Jagt et al. [346] comprising of two Randomised Controlled Trials (RCT) evaluating this communicative health literacy intervention, older adults perceived the photo stories as recognisable, relevant, entertaining and engaging. Participants liked the photo story booklet, felt more motivated, believed that they could understand the content and believed they could apply the information to daily life in terms of action planning or implementation intentions.

The use of a visual aid for those older adults with limited health literacy is largely relevant, supportive of communication and appropriate for this target population. A choice of three presentation formats ensures that the intervention can be flexible and tailored to preferences and requirements of the user. The use of visual stimuli may help to clarify key elements and prompt discussion for users who may find it difficult to navigate a topic of conversation with language that is unfamiliar. The Photo Story Booklet therefore empowers the user to share their thoughts in a less formal manner.

The use of some elements of this intervention may be useful in a care home setting to initiate and maintain discussions around unfamiliar topics that may be sensitive to some. However, there is no inclusion of information about the topic of discussion that would ensure the user understands the topic before discussing it and potentially making decisions.

Talking Mats (Thinking Ahead set)

Talking Mats can be either a physical card resource or digital and offer a visual communication framework which supports people with communication difficulties to express their feelings and views on a given topic. Talking Mats aim to support comprehension and improve quality of conversation. A number of different topics are available, for example ‘Thinking Ahead’ mats which aim to support communication around planning for end-of-life care (see Appendix 6.10). The ‘Thinking Ahead’ Talking Mats resource encourages and supports conversations about care and treatment wishes, affairs, and personal values.

The tool aims to support comprehension of a topic in a number of ways. By breaking down information into small, manageable chunks the user is supported to process concepts more easily. The flexible process of working through the Talking Mats allows users to process information and respond in their own time, and the cards also reduce the demand for memorising information. Conversation quality is improved by the use of Talking Mats as they allow the thinker to be in control of the conversation, provide a structured framework for open questions, reduce anxiety because of less demands, and support the user to express how they really feel.

A study by Boa et al. [368] evaluating the ‘Thinking Ahead’ Talking Mats to support advance care planning with people living with neurological conditions reported high levels of engagement and involvement, and that Talking Mats enabled people to see what they need to do in relation to planning ahead. Although initial feedback suggested that people with neurological conditions benefitted from using Talking Mats to plan ahead, authors suggest that barriers include professional gatekeeping around who should have these conversations and so it is possible that further work is needed to explore how is best to introduce Talking Mats, and training may be required to ensure professionals can use Talking Mats and hand over control to the person and their family.

Out of all of the included existing interventions, Talking Mats met each of the suggested desired target areas for a successful intervention for care home residents from stakeholders (Table 5.4). Talking Mats aim to support comprehension of a topic and improve quality of conversation for those with communication difficulties which would benefit the majority of care home residents.

The flexibility and adaptability of the resource would be suitable for care home residents who may vary in their abilities, and the visual nature of the tool is also desirable as mentioned in our previous studies by residents. The structured yet adaptable framework allows the user autonomy to control the conversation without pressure of maintaining and developing discussion. Further, the more informal visual framework, which can be used with whomever the user is most comfortable, boasts success for an intervention tackling discussions about potentially sensitive topics with care home residents.

Your Life, Your Choices

The Your Life, Your Choices resource has been developed by Pearlman and colleagues [348] and can be used by anyone who needs support to plan for future medical decisions and prepare a personalised will. The information workbook on advance care planning comprises of two parts: The Basics and Resources (see Appendix 6.11). ‘The Basics’ part includes 14 pages which introduce and discuss all of the important components of advance care planning, aiming to provide enough information for the user to figure out what they want and to express their wishes. The second part, ‘Resources’, includes additional help and further explanation of ideas and topics introduced in Part One. Developers suggest that the targeted population use the resource in one of two ways: 1) spend an hour working through the basics and then communicate; 2) work through the basics, then the resources, then communicate.

Pearlman’s work encompasses theoretical and empirical underpinnings of better advance care planning, including the concept of stages of change in behaviour [55]. The stages of change represent attitudes, intention, and/or behaviours that are relevant to an individual’s status in the process of change. Five basic stages of change have been identified and can be applied to ACP: (1) precontemplation (not aware of need for ACP, unwilling or discouraged about completing an advance directive); (2) contemplation (consideration of completing an advance directive); (3) preparation (gathering information, intending to talk about treatment preferences or complete an advance directive); (4) action (actual completion of an advance directive and communication to significant others and health care providers), and (5) maintenance (repeat ACP discussions, updating of advance directive over time).

This organising model of behaviour change is important for ACP, since it explicitly recognises that change is an extended, complex process, and that individuals are at different stages in thinking about and engaging in ACP. Further, complementing the suggested stages of change organising concepts, the Health Belief Model (HBM) helps to analyse and promote behaviour change. The model states that behaviour change comes about by addressing (1) perceived threats (susceptibility or risk if one does not have an advance directive and severity or seriousness of the outcome, i.e. wishes will not be followed); (2) perceived benefits (e.g. increase in patient autonomy, help family members speak on one's behalf); and (3) perceived barriers (e.g. disagreement among family members, time and effort required).

The Your Life, Your Choices intervention includes a section specifically for introducing and discussing important aspects of advance care planning and, for its target population is relevant. However, the self-guided and less personal approach may not be the most effective for care home residents considering what stakeholders have shared. The written document format is not favourable for care home residents' needs. The lack of flexibility and adaptability of the intervention also does not provide supportive verbal communication required by care home residents or promote empowerment. Further, whilst the intervention may be appropriate for the more independent targeted user, the less personal approach and inability to ask questions may leave care home residents struggling to engage with the discussion about a potentially sensitive topic.

6.5 Discussion

It is apparent from the work presented in this thesis chapter that existing interventions and resources to support decision-making around care and life choices for older adults can be successful in supporting their target populations. Further, identifying and understanding the theories underpinning the development of the included existing interventions and resources, specifically for older adults, lends support to the next stage of this project in which theory is intended to inform intervention development.

Considering the thesis aim of developing an intervention to support the inclusion of care home residents in research, the existing interventions and resources identified and discussed in this chapter have been able to lend support to recommendations and reflections made about possibilities to inform the project’s next development stage. Some of the recommendations made, for example context appropriateness and relevance to residents, are applicable to general interventions aimed at supporting communication for advance planning more broadly, and some, such as raising awareness about research, relate more specifically to those aimed at supporting communication about research preferences.

Some of the interventions and resources discussed contain adaptable features which may be appropriate to consider in the development of an intervention to support communication about research participation for care home residents. Areas of importance to target in the development of an intervention for care home residents, as suggested by stakeholders throughout previous chapters, can be seen in some of the included existing interventions and resources which aim to support older people to make decisions about life and care choices.

The possibility of adapting the CC framework is particularly of interest moving forward in the development of an intervention supporting care home residents to share their research participation wishes and preferences. Other than the inclusion of an educational resource (which could be developed and added) this framework encompasses principles which may be well suited to the care home population in terms of facilitating sensitive, early discussions around research participation.

Further, the inclusion of a visual resource in the development and/or adaptation of an intervention for care home residents (such as Talking Mats) could be considered as it is apparent that they are widely appropriate and successful in engaging older people, initiating and maintaining discussion about a particular topic, and providing a less formal intervention suitable for this population - all of which are in line with suggestions made by stakeholders for a successful intervention for care home residents.

Considering the input of stakeholders through primary data collection during this thesis, and the research design of many of the discussed interventions and resources during this chapter (e.g., the use of dyads), it has also been useful to think about who should be included in a future intervention design.

6.6 Summary

This thesis chapter reports the rationale for conducting a review on existing interventions and resources to support decision-making about care and life choices for older adults, the process of identifying existing research evidence, and the characteristics of relevant identified interventions and resources. By identifying this existing information, it was possible to consider overlapping interests, build on existing knowledge and awareness of what is already available, and compare the aims and appropriateness of existing interventions and resources with the aims and objectives of the intervention development being undertaken in this project.

Considering the intervention targets of importance as identified by stakeholders in primary data collection for this project, as well as through PPI input, it was also possible to consider the importance and priority of such elements within existing interventions and resources discussed in the present chapter. Doing so allowed me to identify the possibility of adapting an existing intervention going forward to achieve the ultimate aim of this current project.

6.7 Reflections

As I set out to conduct this review, and write this thesis chapter, I considered the stage of the project I was at, and the time required to complete this chapter. Because this chapter was necessary to inform the following stages of intervention development or adaptation, I wanted to make sure I set out to identify appropriate available literature in a systematic way whilst considering this as a brief review. A more in-depth review would have been ideal if I had a considerably longer amount of time to complete it. With this in mind, I decided to select one online database to search, and to follow an adapted systematic review process including relevant and appropriate frameworks and reporting guidelines such as PICO and PRISMA.

I enjoyed the process of searching for, and identifying, relevant interventions and resources which really helped to improve and revise my knowledge of underlying theories and processes for my own intervention adaptation. Reporting the methods section of this chapter was probably the most difficult as I did not follow a specific review method and so did not have a set of systematic reporting guidelines to follow. Instead, I reported what I believed to be important and relevant to my project at this stage.

Chapter 7 – Development of a complex intervention to support care home residents to communicate their research participation wishes and preferences

7.1 Chapter overview

Chapter 7 presents the development and adaptation process of a complex intervention to support care home residents to communicate their research participation wishes and preferences. This chapter follows the first step of the UK MRC guidance framework for the development and evaluation of complex interventions [82] and is largely informed by all of the previous chapters through a systematic process.

This chapter contributes to the overall aim of this thesis: to create an intervention to support residents' involvement in research. The initial stages of complex intervention development identified what was needed: 1) Education; 2) Discussion facilitation; and 3) Documentation of wishes and preferences and this thesis chapter focuses on the adaptation of an existing intervention (identified in Chapter 6) to support the discussion facilitation stage. This chapter also provides insights into stakeholder collaboration and ends with the next steps required to determine the feasibility of the intervention.

7.2 Introduction

Previous chapters in this thesis have identified the barriers and facilitators to the inclusion of care home residents in research, stakeholders' views about the impact these factors may have on the inclusion of care home residents in research, and potential approaches to improve resident research participation. The final stage of this doctoral thesis was to develop or adapt an intervention to support care home residents to engage with research. Through the use of mixed methods approaches, this thesis has identified that challenges in many areas of communication are apparent within the care home environment and between stakeholders. Alongside this discovery have been discussions and suggestions about feasible ways to make improvements and the identification of ways to facilitate residents' communication about their wishes and preferences about research participation.

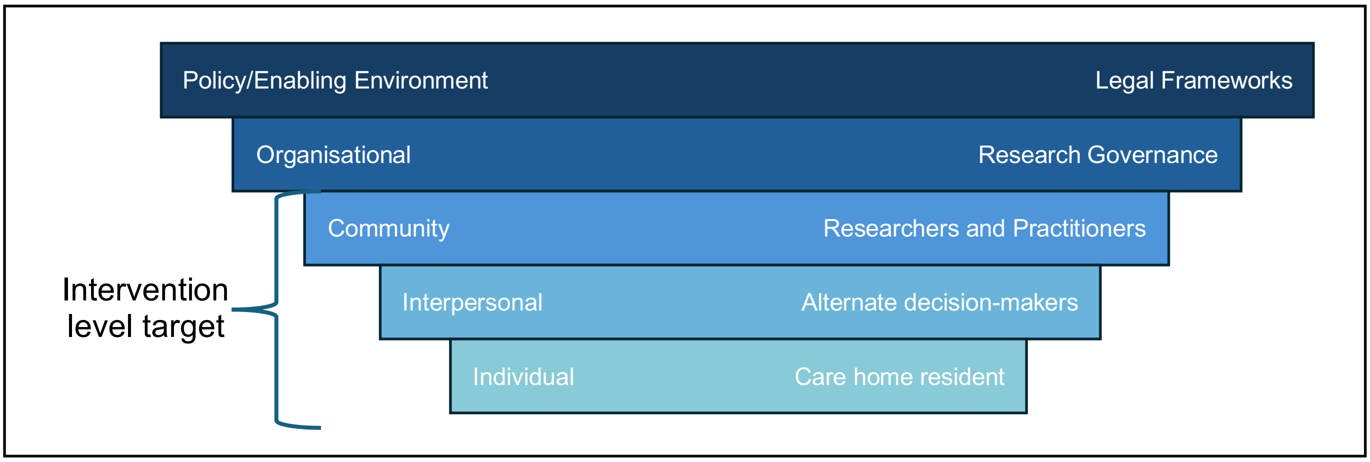
Communication refers to the exchange of information between people, or groups, through verbal, non-verbal, or written methods [369]. The process of communication is interactive and has been described as "*omnidirectional diachronic*", meaning that it requires continuous meaning development [369]. The process is suggested to be multidirectional, and so not limited to one- or two-way communication, but taking place at all levels [369, 370]. Effective communication is essential in many contexts, including both within and between healthcare, social care, and research contexts, as it can facilitate understanding, trust, and collaboration between systems.

Conversation guides are structured tools that can support the facilitation of effective communication [310]. They often include questions or prompts to help guide and focus conversations, ensuring that the most important topics are discussed and that individuals can express their thoughts [310]. The use of conversation guides within care home settings has proven to be successful in other research areas, such as enhancing human interaction [353], advance care planning [371], and end-of-life preferences [372]. Further, visual aids are tools that use images and/or other visual representations that share information or support communication. In the context of care home residents, visual aids can play a crucial part in enhancing understanding and sharing wishes and preferences, as shown in research about end-of-life care in care homes [373], and in research about the mediation properties of visual aids on cognitive decline and sensory impairments in long-term care residents [374].

7.2.1 Considering a socio-ecological systems approach for intervention development

Throughout this thesis, the influence of different system levels has been discussed, including care home residents, relatives, staff, HSCPs, researchers, research ethics committees, and policy makers. The target of the present intervention is situated within complex systems in a wider social context, which interact both directly and indirectly. Research discussing interventions as events within systems proposes five system levels: the policy/enabling environment; organisational level; community level; interpersonal level; and the individual level [375, 376]. Figure 7.1 shows the system levels within a socio-ecological model relevant to this doctoral project and the target level at which this intervention development is focused.

Figure 7.1 A socio-ecological model of the care home setting relevant to this project with the intervention target within complex systems



7.2.2 Chapter aims and objectives

This chapter aims to report the complex intervention adaptation process undertaken as part of this thesis and offer next steps.

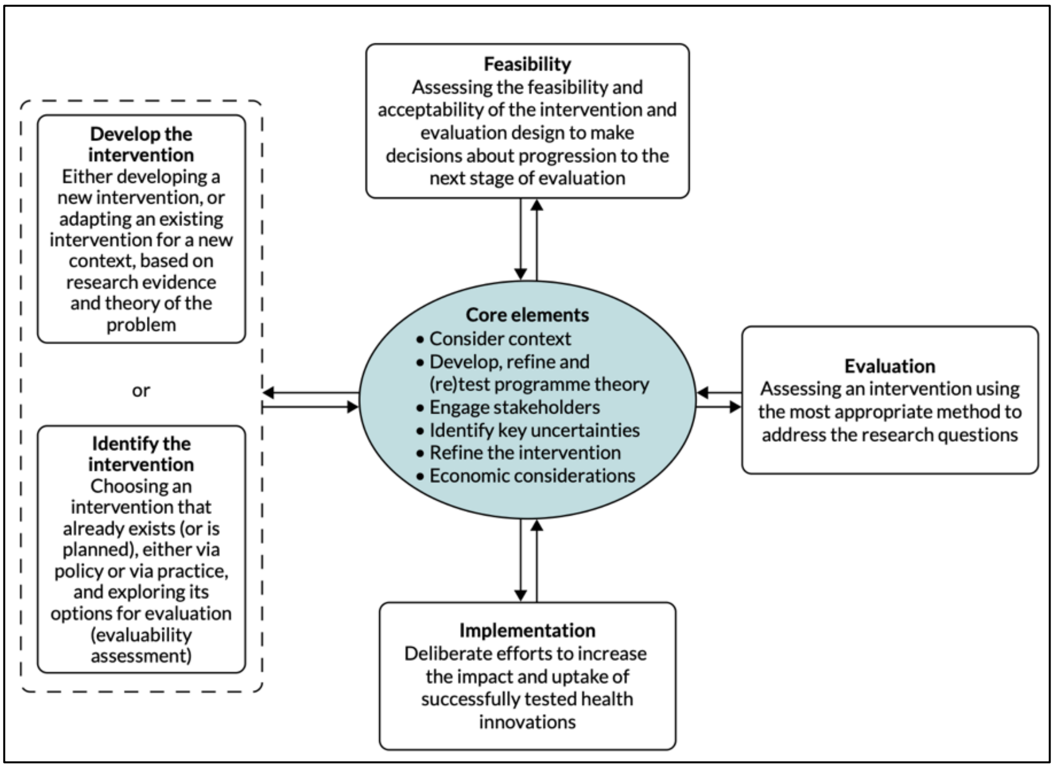
7.3 Complex interventions and the approach taken in this thesis

7.3.1 Theoretical framework

The UK MRC framework for developing and evaluating complex interventions states four phases of research, beginning with ‘developing or identifying the intervention’ [78], and can be seen in Figure 7.2. Development of this complex intervention follows the instructions of the MRC framework, utilising ADAPT guidance [84], funded by the MRC and the NIHR. The MRC framework aims to “improve the design and conduct of complex intervention research to increase its utility, efficiency and impact.” [78].

With its systematic and structured approach, emphasis on theory and mechanisms, focus on iterative development or adaptation of existing intervention, the MRC guidance was deemed the best fit for this stage of the project. Further, evidence of success in diverse fields, including public health, supports its broad applicability compared to alternative frameworks or guidance, such as the Behaviour Change Wheel [377] or intervention mapping [335], which may not be able to offer the same level of applicability or flexibility of intervention development, refinement, and implementation in the complex care home setting [81].

Figure 7.2 MRC Framework for the development and evaluation of complex interventions



7.3.1.1 Core element mapping

The MRC framework proposes a set of six core elements which should be revised continually throughout the process. These core elements include considering context; developing, refining and (re)testing programme theory; engaging stakeholders; identifying key uncertainties; refining the intervention; and economic considerations, as can be seen in Figure 7.2.

Context

Contextual factors such as those which may affect delivery and receipt of the intervention, and those which may affect collection of outcome data, are important to identify and consider in all stages of intervention development. How those identified contextual factors affect the evaluation and/or implementation of the intervention, as well as how contextual dependencies may change for a future evaluation or implementation in different settings [81], are also useful to consider.

Contextual factors worth considering within the ENGAGE study, and our intervention development, include those related to the care home setting. The physical care home environment, daily routines, differing culture within individual care homes, and available resources (i.e., physical resources, staff, relatives, time etc.) all have the potential to affect delivery and receipt of the intervention, collection of outcome data, and transferability of the intervention between care homes, or in potential other settings. Further, differing cognitive abilities between individual care home residents may affect delivery and receipt of the intended intervention. Relationships between stakeholders, whether established, strained, or non-existent, have a huge potential to affect delivery and receipt of the intervention. Poor relationships between stakeholders (for example, between relatives and researchers) have been identified consistently in the literature as a barrier to resident inclusion in research and so warrant considering as contextual factors in the development of the intervention.

Programme Theory

Programme theory describes how an intervention is expected to, and under what conditions will, lead to its effects [78]. Causal pathways are shown between intervention content, intermediate outcomes, and long-term goals, as well as how these interact with contextual factors [378]. The programme theory, developed for the present project, is described in section 7.3.3.2 of this chapter.

Stakeholders

Individuals who have a stake in the research questions being addressed, and potential outcomes of an intervention, can play an important role in the development process. It is vital to identify with whom to engage and also to consider potential conflicts of interest or issues [78].

From its inception, the ENGAGE study has placed importance on the inclusion of stakeholders. Included throughout have been care home residents, relatives, care home staff, other HSCPs who work with care homes, and researchers. It may be worth considering that for the majority of these stakeholders, involvement in research has the potential to be time-consuming and requires resources that may be limited (e.g., care home staff tend to have a high workload with little time to dedicate outside of their work commitments). In addition, there may be a general lack of interest in research for some stakeholders.

As such, it may be important to consider that motivation and recruitment may pose an issue in phases of the intervention implementation.

Key uncertainties

Key uncertainties related to intervention development can be identified by considering what it is we need to know and find out, and also what the priorities are for the future evaluation of the intervention [78]. These may include considering:

- Importance of discussions about research participation to different stakeholders
- Potential influence from wider systems
- Acceptability of the intervention
- Intended outcomes
- Practical implementation of the intervention

- What happens with the outcome/decisions discussed and made during the conversations?
- Could there be any possible unintended consequences or harms that could arise from the intervention?

Refinement

Considering refinement of different aspects of the intervention during the main phases of complex intervention research is important to ensure the best chances for success at future evaluation and/or future implementation [78].

Elements of the present intervention that may be worth refining during the development stage, and in future stages, may include the content and/or delivery of education resources, and discussion facilitation resources. Further, consideration of the timing of, and environment in which early discussions are to be facilitated, would be beneficial as well as the way in which wishes and preferences may be documented and used going forward.

Economic Considerations

It is important to consider the potential costs of the intervention during the development process [78]. Logistical issues with collecting resource use data, additional qualitative and/or process evaluation data, and potential economic evaluation frameworks are all worth considering [78].

There will likely be costs associated with the printing of hard copy conversation guides and visual resources to support care home residents' communication. Incentives may be beneficial or even necessary to recruit stakeholders during the development, feasibility testing, and implementation phases, and should be considered too.

7.3.2 Reporting guidelines

Reporting guidelines are often used by researchers to enhance transparency, consistency, and quality of research reporting [379]. They provide a structure which helps standardise research reporting, ensuring that critical information is included and that studies are easy to understand, replicate and evaluate. This promotes thoroughness and rigor in study design and reporting [380]. As discussed, the MRC provides a checklist for developing and evaluating complex interventions [78]. A completed version of this, reporting the present development stage in this project, can be seen in Appendix 7.1.

7.3.3 Adapting a complex intervention using the ADAPT guidance

The ADAPT guidance emphasises a focus on the inclusion of stakeholders in intervention adaptation; the identification and selection a suitable evidence informed intervention; the planning and carrying out of adaptations; the evaluation of adapted interventions; the implementation of adapted interventions in routine practice; and the reporting of the adaptation processes and outcomes [84, 381]. The guidance comprises of four main steps to adapting interventions to new contexts: 1) Assess rationale for intervention and consider intervention-context fit of existing interventions; 2) Plan for and undertake adaptations; 3) Plan for and undertake piloting and evaluation; and 4) Implement and maintain adapted intervention at scale. The ADAPT process model for adapting interventions to new contexts can be seen in Figure 7.3 and the stages in relation to the work presented in this thesis can be seen in Table 7.1.

Figure 7.3 Adapt process model for adapting interventions to new contexts

Purple boxes=stages of ADAPT step-by-step guidance. Grey boxes=potential outcomes from each stage. Directional arrows=recommendations for moving, forward, or backwards through stages (or exiting), reported by Graham et al. [84].

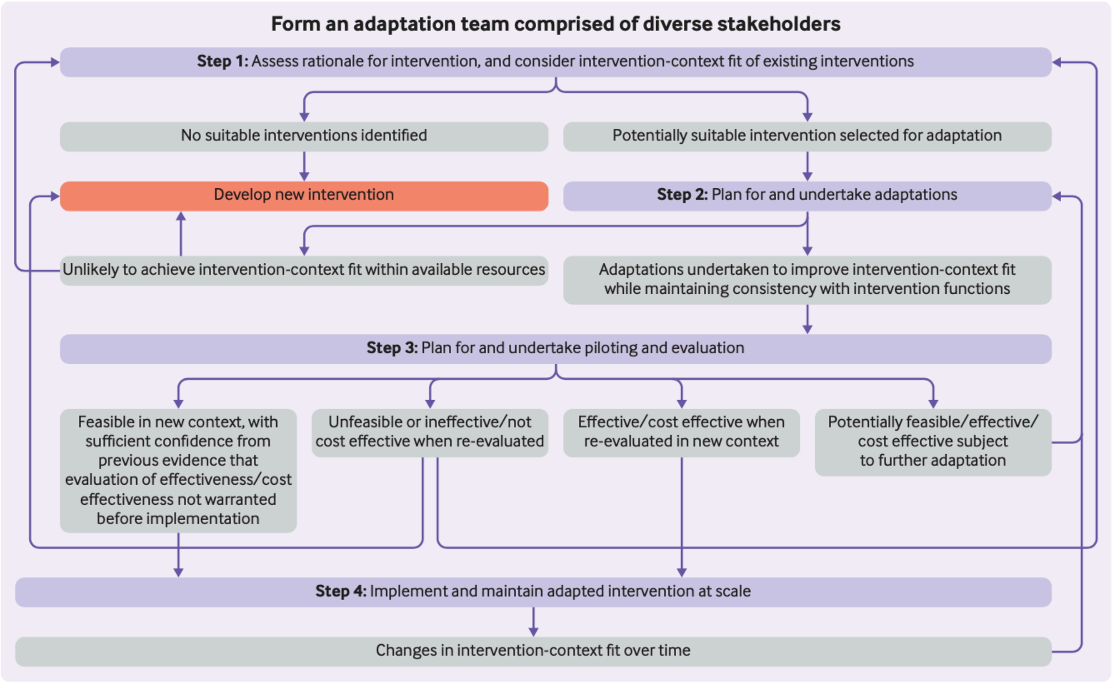


Table 7.1 The ADAPT guidance steps and location in this thesis.

Step in ADAPT guidance	**Reported in thesis chapter**
Step 1: Assess rationale for intervention, and consider intervention-context fit of existing interventions	Chapter 6
Step 2: Plan for and undertake adaptations	Chapter 7
Step 3: Plan and undertake piloting and evaluation	Started in Chapter 7 – next step (post thesis)

Involve stakeholders early and throughout the adaptation process

Stakeholders can help to identify priorities, problems, and solutions, all of which can benefit future implementation of the intervention. A coproduction process was utilised including stakeholders in order to collaboratively generate ideas and make decisions together throughout the development process about the intervention content, format, style and delivery. Ongoing consultation meetings have taken place with a PPI group since the ENGAGE study commenced which have helped gain an understanding of the problem context. In addition, stakeholders' views have been obtained throughout the project through primary data collection, as reported in previous chapters. Through the intervention development process, further involvement of stakeholders was carried out.

PPI meeting

During this stage of the project, a meeting took place in July 2024 with one member of the PPI group who is both a relative of a care home resident and an experienced researcher. The overall aims of this meeting were to discuss the intervention development to date, discuss initial resource development, and gain their feedback. A presentation slide deck including a brief outline of steps taken since the last PPI meeting, intervention development progress, and resource prototypes was sent to the PPI member a week prior to the meeting. The outcomes of this meeting are detailed later in this chapter in section 7.4.2.

Wider stakeholder event

A wider stakeholder event was also held, following intervention refinement, and is described in section 7.5.1.

Agree principles for decision-making and involvement of members

This project was undertaken by the PhD student with support from a supervisory team consisting of researchers with expertise in:

- Care home research including legal aspects of participation
- Complex intervention development
- Behaviour change science
- Qualitative and quantitative methods
- Nursing and social science

7.3.3.1 Step 1: Assess the rationale for intervention and consider the intervention-context fit

The ADAPT guidance suggests that the following are considered in the first step of intervention adaptation: 1) Define the problem in the target population; 2) Identify candidate interventions; 3) Obtain detailed information on the selected intervention and the contexts in which it has been evaluated; 4) Consider the robustness of effectiveness claims; and 5) Map similarity and difference between original and new contexts.

The problem has been identified through a scoping review (Chapter 2), primary data collection (Chapter 3 and 4), and extensive PPI involvement, undertaken as part of this thesis, prior to the present intervention adaptation stage. A review of existing relevant interventions and resources have been reported and discussed in the previous chapter of this thesis (Chapter 6) and, from this, the most suitable existing intervention, subject to adaptations, is the Caring Conversations (CC) framework which has been discussed at length in Chapter 6.

7.3.3.2 Step 2: Plan for and undertake adaptations

The development of a programme theory and logic model

The MRC [78] state the importance of developing and refining a programme theory which considers and describes key components and mechanisms of the intervention and how it will interact with the context specific to its implementation. The programme theory relevant to this work is detailed below and presented in a logic model in Figure 7.4.

Purpose

The purpose of the intervention is to increase opportunities for care home residents to be included in research by being supported to communicate preferences for future research participation through early discussions. The paucity of research evidence to improve the health and social care, and quality of life, of older adults living in care homes due to their underrepresentation in research motivated the need for this intervention.

Context

In addition to the contextual factors discussed in section 7.3.1.1, it is worth considering factors that the intervention is not able to address such as the numerous other identified barriers to resident inclusion in research. These include, for example, barriers resulting from research design and study eligibility criteria, which are beyond the scope of this intervention. Further, it is useful to consider the wider systems which may have an interest in intervention research in this care setting, such as owners of care homes, the community, health and social care systems, and the NHS. This may also include consideration of the political and economic climate for investing in improving care home research which has become more of a priority following the COVID-19 pandemic.

Input/resources/implementation

The implementation of this intervention will require the participation of a care home resident, a ‘trusted person’ of the resident’s choosing (e.g., relative), and potentially a facilitator who may be a researcher or member of care home staff.

The intervention will be received in the care home setting and comprises of three stages: 1) education; 2) discussion facilitation; and 3) documentation of wishes and preferences. The focus of this project’s intervention is stage 2: discussion facilitation which presents the adaptation of an existing intervention identified in Chapter 6. The communication support intervention will comprise of a set of facilitative questions (i.e., a conversation guide) based on the CC framework [310]. Visual resources depicting key concepts and information will also be available to support discussion and allow tailoring of the information to different needs of potential participants perhaps on the basis of their health and research literacy or their visual and auditory needs.

Communication support has been identified as the most important issue to target during previous stages of qualitative investigations with stakeholders. These include raising awareness, making it relevant, supporting communication, and appropriateness. Raising awareness can be achieved by providing information about what research is, the different types of research design, and potential benefits and consequences of conducting and participating in research. Additionally, ensuring potential participants are aware of their options, including the acceptability of changing their mind, is important. Making the intervention relevant can be achieved by ensuring flexibility and relevance of the intervention to targeted individuals are considered throughout. Further, communication support is to be largely considered, as well as the ability to tailor the intervention to the communication abilities and accessibility needs of individual care home residents to ensure effective engagement. Appropriateness of the intervention for each resident will be ensured by considering the most suitable conditions (e.g., how, when, where, with whom) under which discussions will be facilitated.

Outputs (activities, mechanisms of impact, intervention and participants)

The resources developed (i.e., a toolkit) will be used to facilitate discussions about research participation with care home residents and their trusted person(s) and support communication of their research participation wishes and preferences.

In addition to the question set developed to support facilitation of early discussions, visual aids will be presented to provide additional support to care home residents who may have additional needs. The use, or not, of these visual aids presents an opportunity to tailor the intervention to individuals' needs and to ensure that the discussion is accessible for all care home residents who are eligible to have these early discussions about their future research wishes and preferences. The addition of visual aids has been influenced by visual resources such as Fink Cards [342] and the Photo Story Booklet [346, 382]. Theories underpinning the development of existing visual aids to support discussion facilitation and decision-making about care and life choices for older adults include social learning theories, theories of behaviour change, and theories of motivation. For example, Listening, Sharing Power, Responsive Action, and Connecting with Citizenship are the principles of

Person-Centred Practice which underpins the development of the Fink Cards resource [342]. The foundation of the Listening principle lies within the Person-Centred Counselling and Therapeutic Model [363]; Self Determination Theory (SDT, [352]) underpins the importance of the Sharing Power principle; the Exchange Model, featured in Smale's work [364] offers explanation to Responsive Action; and, informed by the work of the Inclusion Movement, the Citizen Model [365] offers an understanding of the importance of connecting with citizenship. The Connecting with Citizenship principle [365], informed by the work of the Inclusion Movement, proposes six 'keys' that collectively enable us to achieve full citizenship: 1) Self-determination; 2) Money; 3) Direction; 4) Home; 5) Support; and 6) Community Life.

Further, theories underpinning the development of the photo story booklet resource include theories of narrative mechanisms and theories of social and observational learning. For example, Schank and Abelson [367] posit that virtually all of the important social knowledge is composed of stories that people either construct from their own life experience or learn from other sources. Theories of social and observational learning are grounded in Social Learning Theory (SLT) which states that observation and imitation of others' behaviour results in learning [220], hence the photos used in the booklet portraying typical behaviours in the setting for those with limited health literacy to consider and base their own behaviours on.

The appropriate documentation of discussion outcomes will need to be finalised in later stages of this intervention development (proposed Stage 3). This may be within residents' care home notes or as part of an advance research directive.

This intervention aims to reach care home residents and their trusted person(s) who would benefit from knowing their research participation wishes and preferences. A resident's trusted person may be a relative, care home staff member, or power of attorney, who may need to make decisions about the resident's research participation in the future, should they lose capacity to consent for themselves. Residents who participate in these early discussions about their research participation will need to have capacity to consent for themselves at this stage.

Outcomes/Effects

In the short-term it might be expected that following completion of Stage 1 (education) and Stage 2 (discussion facilitation), both individuals in the resident/trusted person dyad will have a better understanding about research generally. This will include knowledge about how to find research opportunities, different types of research design, awareness about the possible benefits and consequences of research, and residents' options regarding research participation. In the short-term it might also be expected that the intervention will provide an opportunity for care home residents to communicate their research participation preferences, and for future personal consultees to become aware of these.

Further, in the mid-term, it would be expected that participation decisions made by another person on behalf of care home residents who have lost capacity to consent for themselves, are more closely based on the resident's wishes and preferences shared during the facilitated early discussion. As a result it is hoped that care home participation in research will increase.

Lastly, in the long-term, it is hoped to see improvement of the inclusion of care home residents in health and social care research that can influence beneficial changes in evidence-based health and social care for care home residents and improve their quality of life.

Figure 7.4 Logic model development (see next page)

PURPOSE - To increase opportunities to be included in research for care home residents by using an intervention to support communication through early discussion about research wishes and preferences

INPUTS	OUTPUTS		OUTCOMES – Impact/changes/results		
Resources	**Activities - What we will do**	**Participation - Who will we reach**	**Short-term**	**Mid-term**	**Long-term**
Communication intervention to facilitate early discussions with care home residents care home residents' wishes and preferences for their own research participation considering: *Raising awareness* *Making it relevant* *Supporting communication* *Appropriateness* **Stage 1 - Education** Awareness about what research is and entails will be required by care home residents and their trusted person. The 'trusted person' (i.e., care home staff or relative) will require awareness about how to best support the residents in sharing their research wishes and preferences. An education programme designed specifically to educate care home residents and stakeholders about research is under development by ENRICH and can be used in this first stage. **Stage 2 – Discussion facilitation (PRESENT FOCUS)** This is the focus of the current intervention adaptation stage and will comprise of a toolkit including a conversation guide, consisting of a set of questions designed specifically for focused discussion informed by the Caring Conversations framework, and appropriate visual aids to support communication for the resident and their trusted person. **Stage 3 – Documenting wishes and preferences** Future stage for the project	Use the toolkit resources to facilitate discussion and support communication of research participation wishes and preferences Document discussion in residents' notes or advance research directive	Care home residents and their trusted person who would benefit from knowing their research participation wishes and preferences (relative, POA, care home staff etc.) Researcher to engage care home resident and trusted person dyad Care home resident WITH capacity to consent as this is our target	Stakeholders educated about research generally, the importance of care home residents participating, and being represented, in research and exposed to more opportunities to get involved in research studies Care home residents able to communicate their research wishes and preferences Potential future personal consultees become aware of residents' research wishes and preferences	Participation decisions for residents who lack capacity are more closely based on their wishes and preferences More involvement of care home residents in, and thus representation, in research	Improvement of the inclusion of care home residents in health and social care research Changes in evidence-based health and social care and improved quality of life for care home residents

ASSUMPTIONS:
Increased information about what research is and participation entails will improve stakeholders' attitudes towards participating in research and through discussion of residents' participation wishes and preferences their choices will be better represented should they at any point not have capacity to consent for themselves.
Trusted person (potential personal consultee) knowledge and confidence about residents' wishes and preferences will increase decision quality and reduce burden of decision-making in the future.

EVALUATION:
Ability to express research participation wishes and preferences.

EXTERNAL FACTORS
CONTEXTUAL FACTORS:
Care home environment, routines, culture, resources
Cognitive ability of residents
Relationship between stakeholders/users

7.4 Bringing together the previous work to design the prototype

Continuing with Step 2 of the ADAPT guidance, this section reports how the previous work in this thesis has been triangulated to design the intervention prototype.

7.4.1 Adaptation of intervention content

The CC framework has been discussed in depth in Chapter 6 and has the potential to be successfully adapted and implemented in social care settings because of its emphasis on relational care and its suitability for improving communication between stakeholders [310]. It has been previously applied to improve communication and relationship-centred care across health and social care settings, including care homes [353]. Appreciative Inquiry, as discussed in both Chapters 5 and 6, is the underlying theory on which the CC framework is based.

7.4.1.1 Caring Conversations about research participation wishes and preferences with care home residents

Adapting the CC framework to the development of an intervention aiming to support discussions with care home residents about research participation wishes and preferences has significant potential to be successful. The model's core principles can help to facilitate such conversations in a number of ways.

Firstly, the principle of 'Being Courageous' is important in addressing sensitive or complex topics of conversation, such that can occur through discussion of future research participation following loss of capacity [310]. Engaging in research, as has been discussed in this thesis, often requires researchers to address ethical concerns, informed consent, and potential impact of research on care home residents and other relevant stakeholders' lives [52, 70]. By encouraging transparent conversation, guided by this principle, the framework allows stakeholders to talk openly about potential participation benefits, challenges, and any concerns or worries, thus supporting residents to share their voice and make informed decisions

[353]. Dewar et al. [353] report that encouraging courageous conversations helps to create an environment where residents feel comfortable asking questions and voicing their concerns, crucial when having conversations about research participation where some residents may have reservations about taking part because of misunderstandings or mistrust.

Additionally, emotional engagement is supported through the principle of ‘Connecting Emotionally’ in the CC framework which is important when having discussions with care home residents who often are seen as vulnerable or feel disempowered [310]. Taking the time to engage with residents’ emotionally can ensure that their feelings, as well as any concerns, are listened to, validated, and respected. Doing so may help to reduce any emotional barriers that prevent residents from considering taking part in research. Research has found that emotionally engaging conversations can lead to greater trust and rapport building [353], which is crucial when introducing potentially novel opportunities such as research.

The principle of ‘Being Curious’ offers the opportunity to explore residents’ views and perspectives on research which can allow the conversation partner to gain a better understanding about research knowledge and understanding, opinions, and willingness to participate [310]. By encouraging curiosity and understanding, we may be able to gather valuable insights which can guide how research opportunities are presented in the future to residents who express an interest. Conversations addressing uncertainties about research may be able to identify barriers to research participation and address them.

The principles of ‘Collaborating’ and ‘Compromising’ are important to consider when navigating decision-making processes around research participation [310]. Care homes are complex environments with many stakeholders who often have poor relationships and communication [150]. Collaboration in conversations around residents’ research participation is essential to making sure that all groups are given the opportunity to feel heard and involved in decision-making process whilst respecting residents’ autonomy [106].

Further, care home residents are often excluded from research because of barriers such as cognitive impairment [52]. The CC framework can be used to overcome such challenges by creating inclusive discussion where the voice of the resident is of upmost importance. The ‘Considering Other Perspectives’ and ‘Compromising’ principles allow for the flexibility and accommodation of residents’ individual needs while offering them the opportunity to share their wishes and preferences about research participation. The framework encourages the facilitation of a conversation where residents are treated as active partners rather than passive subjects, fostering empowerment and inclusion [310].

While it is apparent that applying the CC framework to the current work could have a number of clear benefits, there may be some challenges related to context when applying it within the care home setting because of known barriers that have been discussed throughout this thesis. For example, time and resource constraints within the care home setting may impact facilitation of meaningful and reflective conversations using the CC framework. Successful implementation of the model requires the conversation partner to know the resident well enough to have a good level of rapport and trust, as well as be able to make adjustments to the framework guide based on the residents’ needs, level of understanding, and communication abilities. This could make it much more difficult to identify a partner to engage in discussions about research with a resident. Further, consideration of other contextual factors such as the care home environment, daily routines, available resources, and relationships between different systems will need to be a priority in adapting the framework to this complex setting. A previous study, as detailed in Chapter 6, has confirmed that the CC framework is both applicable and relevant to a care home setting [353], however it will be essential to consider factors which may be unclear and may differ between care homes such as resources, research infrastructure, and key stakeholders. These will need to be understood further during intervention refinement and feasibility testing.

7.4.1.2 Initial prototypes

Caring Conversations (CC) framework

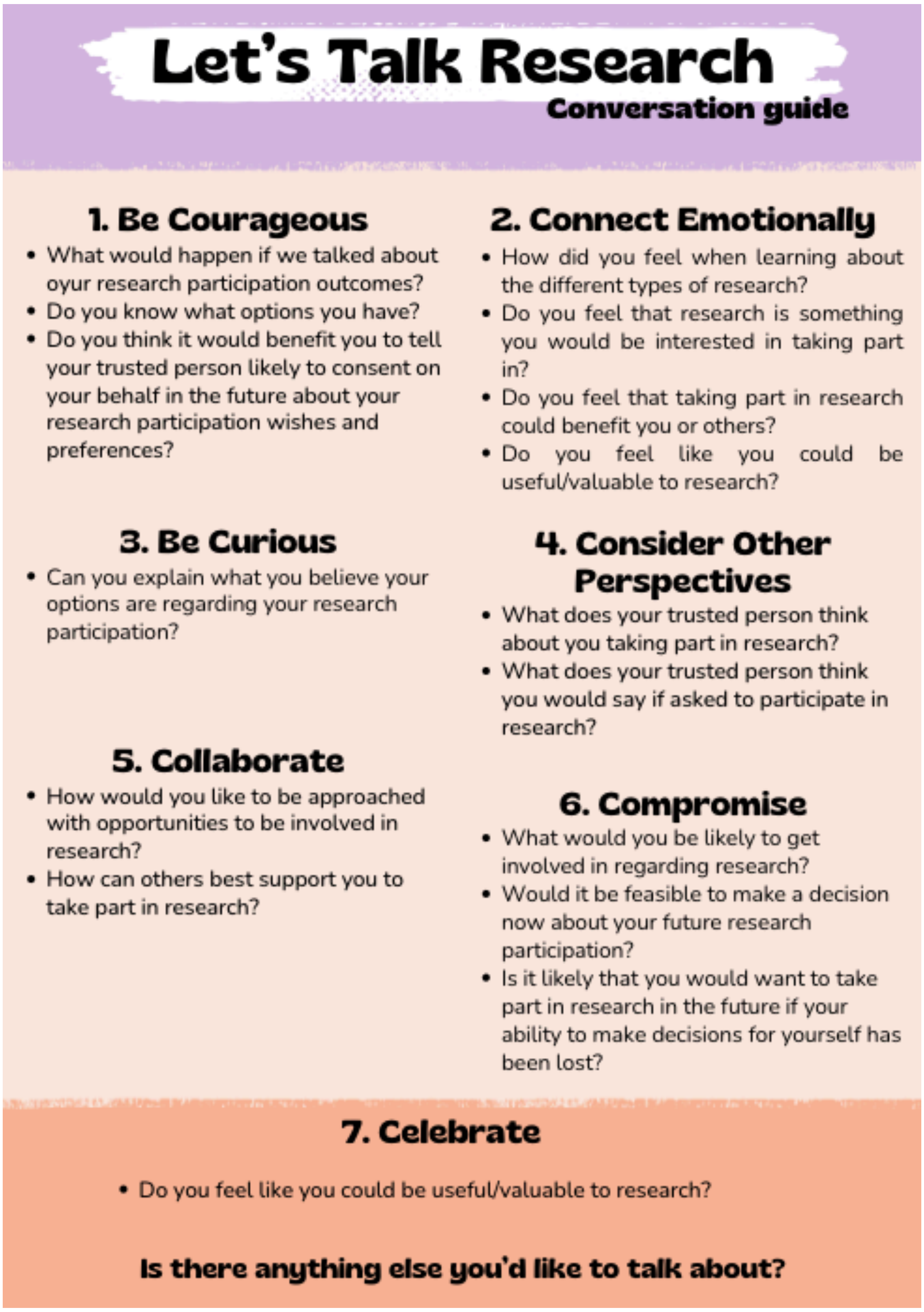
Using the CC framework [310], initial questions relevant to the adaptation of the intervention were created and can be seen in Table 7.2 and Figure 7.5.

Table 7.2 Initial questions developed to be included in a conversation guide resource as part of this intervention adaptation following the ‘7 Cs’ as suggested by the CC framework [310].

7 Cs	
Be courageous *What would happen if we gave this a go?*	What would happen if we talked about your research participation options? Do you know what options you have? Do you think it would benefit you to tell your trusted person/person likely to consent on your behalf in the future about your research participation wishes and preferences?
Connect Emotionally *How did this make you feel?*	How did you feel when learning about the different types of research? Do you feel that research is something you would be interested in taking part in? Do you feel that taking part in research could benefit you or others? Do you feel like you could be useful/valuable to research?
Be Curious *Help me to understand what is happening?*	Can you explain what you believe your options are regarding research participation?
Consider Other Perspectives *What do others think?*	What does your trusted person think about you participating in research? What does your trusted person think you would say if asked to participate in research?
Collaborate	How would you like to be approached with opportunities to take part in research?

7 Cs	
How can we work together to make this happen?	How can others support you to share your research participation wishes and preferences?
Compromise *What is real and possible?*	What would you be likely to get involved in regarding research? Would it be feasible to make a decision now about your future research participation? Is it likely you would want to take part in research in the future if your ability to make decisions for yourself has been lost?
Celebrate *What worked well?*	Do you feel like you could be useful/valuable to research?

Figure 7.5 Initial design of conversation guide



Let's Talk Research

Conversation guide

1. Be Courageous

- What would happen if we talked about oyur research participation outcomes?
- Do you know what options you have?
- Do you think it would benefit you to tell your trusted person likely to consent on your behalf in the future about your research participation wishes and preferences?

2. Connect Emotionally

- How did you feel when learning about the different types of research?
- Do you feel that research is something you would be interested in taking part in?
- Do you feel that taking part in research could benefit you or others?
- Do you feel like you could be useful/valuable to research?

3. Be Curious

- Can you explain what you believe your options are regarding your research participation?

4. Consider Other Perspectives

- What does your trusted person think about you taking part in research?
- What does your trusted person think you would say if asked to participate in research?

5. Collaborate

- How would you like to be approached with opportunities to be involved in research?
- How can others best support you to take part in research?

6. Compromise

- What would you be likely to get involved in regarding research?
- Would it be feasible to make a decision now about your future research participation?
- Is it likely that you would want to take part in research in the future if your ability to make decisions for yourself has been lost?

7. Celebrate

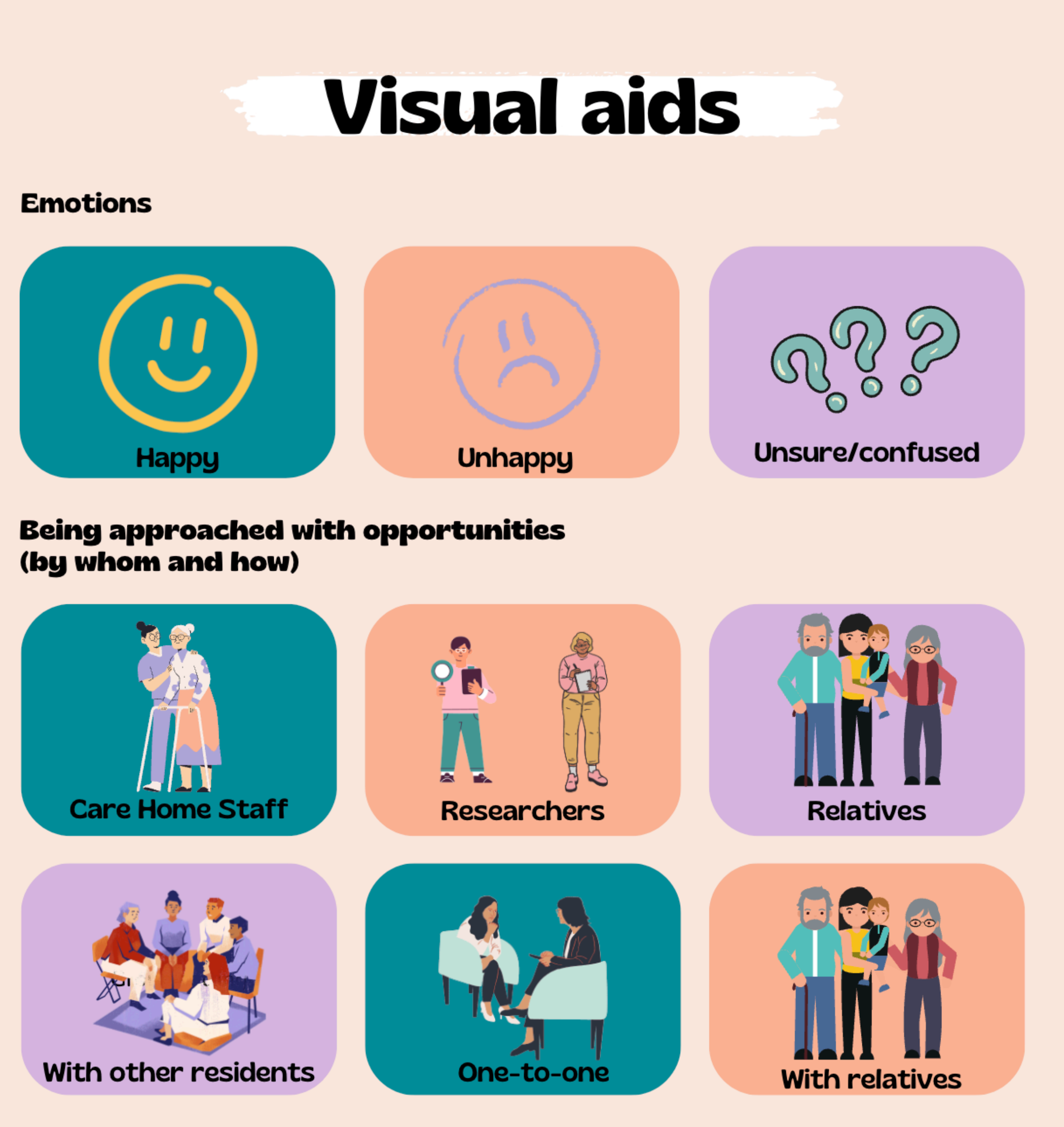
- Do you feel like you could be useful/valuable to research?

Is there anything else you'd like to talk about?

Visual aids

Initial sets of visual aid cards were developed with the aims of helping to further explain questions being asked, and to support residents to communicate their responses to questions (see Figure 7.6). A set of emotion cards were designed to support residents to share their emotions about the task and their responses to questions (i.e., happy, unhappy, confused). Another set included visual aids which support the explanation of, and response to, questions about being approached with research opportunities. These included cards representing people who could approach residents with research opportunities (i.e., researchers, staff, relatives), and cards representing people who residents might prefer to be with when being presented with research opportunities (i.e., alone, with relatives, with other residents in a group setting).

Figure 7.6 Initial design of visual aids



7.4.2 Collaborative development with stakeholders

PPI meeting

The ENGAGE study PPI group member who is both a relative of an older person living in a care home and an experienced researcher, provided feedback about the intervention development and adaptation process so far, including proposed resource content, through discussion with myself alongside a presentation of the work.

In response to the four areas of importance to consider during intervention development, the PPI member suggested that it should be made clearer what the time and task requirements were for care home staff. Further, the PPI member reflected that whilst the logic model looks busy the content appeared very logical and well thought out. It was also suggested by the PPI member that the developers of the Caring Conversations model could be contacted to co-design the questions relevant to this intervention development. With regards to resource content, the PPI member shared suggestions of additional questions under each of the Caring Conversations headings. These included:

Be Courageous
- Did you know research could be a wide range of things? From talking to drug trials.

Connecting Emotionally
- Do you feel included?

Be Curious
- How do you feel about taking part?
- Have you changed your mind after hearing more about research?
- What do you understand research to entail?
- What has changed for you?

Consider Other Perspectives
- What do researchers, relatives, and staff think?

Collaborate

- Could staff be included too?

Compromise

- Are you aware that you can say yes to some things and no to others?

Celebrate

- Have you felt heard?

Further, the PPI member gave recommendations about the appearance and content of the proposed visual aids including their size, colour, use of cartoon pictures, and including images without any words. In addition to these, the PPI member offered advice about the type of emotions to include suggesting that I ask care homes if there are any they regularly use with residents, or any that they believe would be most useful.

During discussion around the planned stakeholder event, the PPI member shared some other suggestions. These included considering having separate events for different stakeholders; potential worries around hosting the event in one care home and inviting staff from other care homes; and considering accessibility of the venue. The PPI member suggested a community hall may be an idea for a neutral location.

Changes made in response to PPI recommendations included:

- The addition of questions to the conversation guide resource
- Sizing and appearance of the visual aids
- Inclusion of ‘thumbs up’ and ‘thumbs down’ visual aids
- Request of input from care home staff regarding the appropriateness of the visual aids when planning the stakeholder event

Refined prototypes

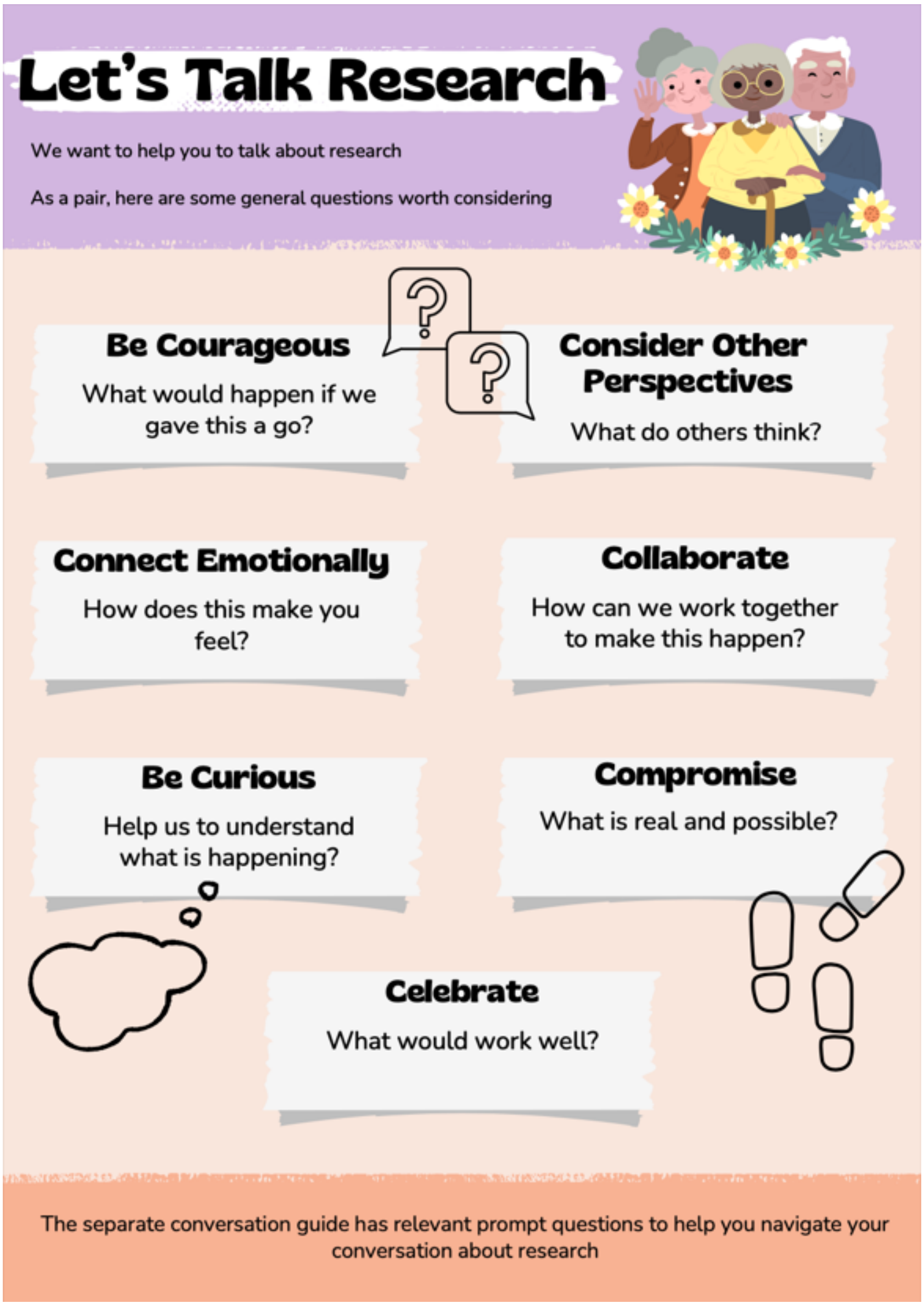
After the PPI consultation, I met with my supervisors to discuss other ways to improve the resources, considering the key factors identified through primary data collection, and following this made further refinement decisions, which included:

- The inclusion of an additional briefer document for residents
- Design changes (font, placement of text etc.)

- Addition of ‘tips’ for user on conversation guide document
- Additional visual aid cards

And so, it was decided that together, these resources would make up a ‘toolkit’ for the intervention ‘Let’s Talk Research’. The refined prototypes can be seen in Figures 7.7, 7.8, and 7.9.

Figure 7.7 – Brief accessible conversation guide (targeted at resident)



Let’s Talk Research

We want to help you to talk about research

As a pair, here are some general questions worth considering

Be Courageous
What would happen if we gave this a go?

Consider Other Perspectives
What do others think?

Connect Emotionally
How does this make you feel?

Collaborate
How can we work together to make this happen?

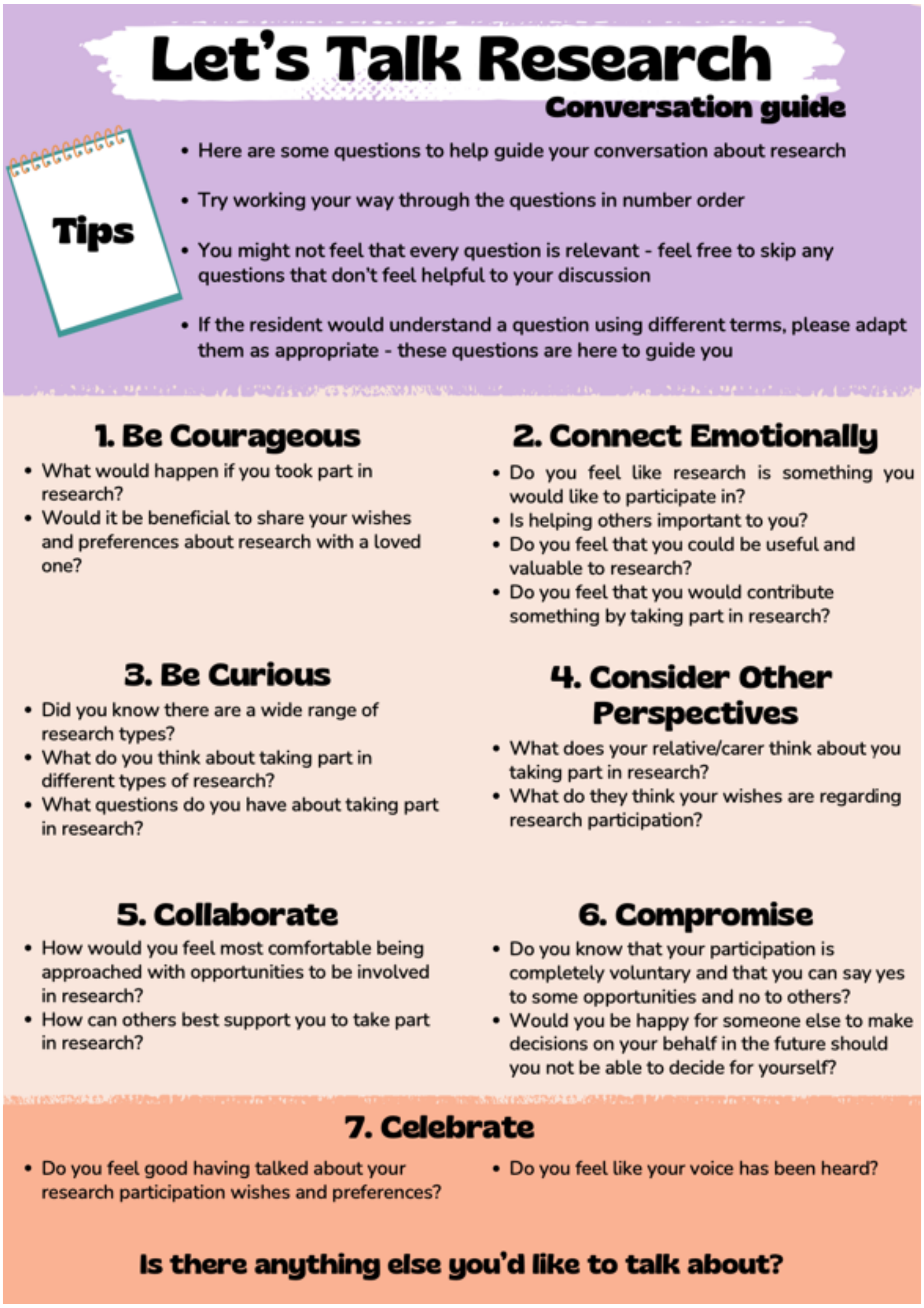
Be Curious
Help us to understand what is happening?

Compromise
What is real and possible?

Celebrate
What would work well?

The separate conversation guide has relevant prompt questions to help you navigate your conversation about research

Figure 7.8 – Detailed conversation guide (targeted at trusted person)



Let's Talk Research

Conversation guide

Tips

- Here are some questions to help guide your conversation about research
- Try working your way through the questions in number order
- You might not feel that every question is relevant - feel free to skip any questions that don't feel helpful to your discussion
- If the resident would understand a question using different terms, please adapt them as appropriate - these questions are here to guide you

1. Be Courageous

- What would happen if you took part in research?
- Would it be beneficial to share your wishes and preferences about research with a loved one?

2. Connect Emotionally

- Do you feel like research is something you would like to participate in?
- Is helping others important to you?
- Do you feel that you could be useful and valuable to research?
- Do you feel that you would contribute something by taking part in research?

3. Be Curious

- Did you know there are a wide range of research types?
- What do you think about taking part in different types of research?
- What questions do you have about taking part in research?

4. Consider Other Perspectives

- What does your relative/carer think about you taking part in research?
- What do they think your wishes are regarding research participation?

5. Collaborate

- How would you feel most comfortable being approached with opportunities to be involved in research?
- How can others best support you to take part in research?

6. Compromise

- Do you know that your participation is completely voluntary and that you can say yes to some opportunities and no to others?
- Would you be happy for someone else to make decisions on your behalf in the future should you not be able to decide for yourself?

7. Celebrate

- Do you feel good having talked about your research participation wishes and preferences?
- Do you feel like your voice has been heard?

Is there anything else you'd like to talk about?

Figure 7.9 Visual aids

7.5 Testing the prototype

7.5.1 Wider stakeholder event

A wider stakeholder event was arranged for September 2024 at a care home whose residents had been involved in previous stages of the ENGAGE study, as reported in this thesis. ENRICH Cymru were contacted to identify potentially interested care homes for this stage of the project who were then contacted directly by myself. The home in which the wider stakeholder event took place was a medium sized residential home in an urban area of South Wales providing care for 30 residents living with and without dementia or other conditions.

Following an expression of interest to be involved by the assistant manager, detailed information was shared by email about what the event would entail, and what would be required from the home. Following this two in-person visits were undertaken to plan the event. The first in-person meeting was to explain the project to date, discuss requirements of the event, and get feedback on the suitability of the resources for their residents. The second in-person meeting comprised of logistical planning for the event and a reminder of the necessary factors that needed to be met for the event to be successful, including internal advertisement of the event to residents and relatives; only residents with full capacity to be involved; and the crucial need for residents to be in a pair with their ‘trusted person’. The planned agenda of the 90-minute session was discussed with the assistant manager and confirmed as appropriate, including:

- Introductions
- Showing of a brief video about what research is, developed by Health and Care Research Wales (https://www.youtube.com/watch?v=jM594zRlnjU)
- A brief background to the ENGAGE study
- Purpose of the intervention
- The task, what is required, and an explanation of the resources
- An attempt at having a conversation about research using the resources
- Debrief and general discussion about the task
- Completion of feedback forms
- A later catch-up with the assistant manager to gain feedback

Opportunities for questions were given and encouraged throughout the event. See Appendix 7.2 and 7.3 for the stakeholder event poster and feedback form. The event was planned to take place around morning tea and coffee with the residents and their relatives, with refreshments supplied by the ENGAGE study. Supervisor FW also attended the stakeholder event to provide support, take pictures, and field notes. Pictures of the event can be seen in Appendix 7.4.

The wider stakeholder event was held on 18/09/2024. 11 residents attended but were not in dyads with a ‘trusted person’ as recommended. It also was apparent that the majority of the residents who attended did not have the capacity to meaningfully engage in discussions about their research wishes and preferences. One relative joined the session at a later time and so missed the initial introductions, purpose of the event, instructions, and conversation facilitation, but provided feedback on the resources. BN and FW carried out the discussions with each of the residents who attended the event and were able to engage, acting as the ‘trusted person’ in the dyad. Feedback sheets for each resident were completed by BN and FW and the resident following the use of the toolkit resources. Responses can be seen in Table 7.3.

Table 7.3 Responses to feedback statements

	No. (%)
“The toolkit was easy to use.” (*n* = 9 responses)	
Strongly disagree	4 (44.4)
Disagree	2 (22.2)
Neutral	1 (11.1)
Agree	2 (22.2)
Strongly agree	0 (0)
“The toolkit helped guide us to talk about research.” (*n* = 8 responses)	
Strongly disagree	1 (12.5)
Disagree	0 (0)
Neutral	2 (25)
Agree	5 (62.5)
Strongly agree	0 (0)
“The purpose of the toolkit was clear.” (*n* = 9 responses)	
Strongly disagree	1 (11.1)
Disagree	2 (22.2)
Neutral	1 (11.1)
Agree	5 (55.5)

Strongly agree	0 (0)
“The information and content were easy to understand.” (n = 8 responses)	
Strongly disagree	3 (37.5)
Disagree	4 (50)
Neutral	1 (12.5)
Agree	0 (0)
Strongly agree	0 (0)
“The design and colours were appealing.” (n = 8 responses)	
Strongly disagree	1 (12.5)
Disagree	0 (0)
Neutral	1 (12.5)
Agree	5 (62.5)
Strongly agree	1 (12.5)

General observations, verbal, and written feedback

Overall the residents expressed their enjoyment of attending the event saying that it was *“very well organised”* and that they *“enjoyed it very much today … it was wonderful”.* A general positive attitude towards research and helping was observed.

General issues regarding eyesight and being able to read the resources were flagged by a number of the residents, which made it difficult for them to engage with the materials. One resident shared that they could not hear very well, with engagement made more difficult by the noise in the room in the group session.

Another resident talked about how she found living in a care home *“very restrictive”* in terms of being able to go out and do anything she would like, and in staff she feels she can talk to or trust. This particular participant engaged well and found certain words on the resources (e.g., “courage”) useful as prompts for discussion. However, the resident thought it might mean courage to face the future (or near death) and so it was necessary to reiterate the meaning of the task. Another resident shared that they *“felt a bit curious”* when they saw the headings on the conversation guide too.

Another resident had reasonable eyesight and was a good reader, enjoying talking with the researchers. She said that research *“makes me feel dull” (*i.e. stupid). She was asked about the types of research she might like to be involved with, for example, research about new medicines and replied, *“I’m not sure, I don’t know which way it would go”*. It was then clarified that she was referring to possible risks of participation. Preferences about the sharing of research opportunities were discussed and she said it was easier to *“talk in a group”* rather than one-to-one because they prefer to *“be in the background”.* She shared that she might feel most comfortable with her daughter too. This participant really liked the visual aid cards although reported that the unhappy face on the small card was *“hard to see”.*

One resident’s niece arrived towards the end of the session and, although missing the introduction and instructions for the session and resources, provided some feedback:

“I feel the headings are difficult for the residents to understand and it would be helpful if they were in plain English” and *“I missed the talk but just giving out the written toolkit is not clear for my uncle to understand”*

Another resident was able to engage in a focused conversation well. She struggled to read the text so relied on her partner to explain and rephrase words as appropriate to her needs and understanding. This participant discussed that she would be happy to hear about opportunities to get involved in research and that on a one-to-one basis would suit her more, but actual participation would depend on what the research was about. If it was *“too personal”,* then she *“might not want to”.* This resident shared that the topic of the research would also influence who she would rather be approached by with the opportunity. For example, she shared that if the topic was very personal she may not wish to talk to a researcher/stranger or staff member but would be happier with her daughter. This participant had reservations about whether she was suitable or would be useful as a research participant, sharing that she used to be a teacher but described herself as *“dull now”*.

7.6 Next steps for the intervention and design of its feasibility study

7.6.1 Further intervention refinement

Areas to consider for intervention refinement include the accessibility of the resources, and so further work will need to be done to create a version of the toolkit resources using accessible design principles. Additionally, upon reflection of the wider stakeholder event, further consideration about how the intended aims of the sessions are communicated to the care home is crucial. This would include ensuring the communication of who would be eligible/appropriate to join or use the intervention, and perhaps how care home staff could enhance the facilitation of the session.

It was felt that an additional small pilot of the intervention, including revised instructions and guidance to the care home about the aims of the session, would be necessary to refining these factors before moving on to feasibility testing.

7.6.2 Establishing feasibility

Following the first stage of complex intervention development and evaluation, the MCR guidance suggests establishing the feasibility of the intervention. The guidance states that:

“A feasibility study should be designed to ***assess predefined progression criteria*** *that relate to the feasibility and acceptability of the intervention and/or the evaluation design.” [78]*

Eldridge and colleagues [383] share that the purpose of a feasibility study is to establish whether something can be done, if it should be proceeded with, and how.

Feasibility studies have also been suggested to be a further step in refining an intervention [384].

The MRC guidance states the following must be considered to assess feasibility and acceptability of the intervention design: 1) optimal content and delivery; 2) acceptability; 3) adherence; 4) likelihood of cost effectiveness; and 5) capacity of providers to deliver the intervention. Further, the feasibility of the evaluation design will must consider: 1) recruitment; 2) retention; 3) sample size; 4) outcomes; 5) analysis; and 6) unintended outcomes. The MRC guidance also offers six core elements to consider for the feasibility phase of intervention development and evaluation: 1) Context; 2) Programme theory; 3) Stakeholders; 4) Uncertainty; 5) Intervention refinement; and 6) Economic considerations.

7.6.2.1 Proposed feasibility study protocol

This section presents an outline of the next proposed stage of the project, a study aiming to explore initial feasibility of the intervention, detailing aspects of the proposed study including recruitment processes, outcome measures, progression criteria, and evaluation measures. A proposed study flow chart can be seen in Figure 7.10.

Study design and setting

This protocol is an outline of the proposed next stage of the project. I have been successful in my application for Health and Care Research Wales' Next Step Award grant to continue this research, following the end of my PhD project. This generous and prestigious award provides an opportunity for former PhD studentship award holders to be supported to work their project to the next stage and prepare for research fellowship applications. ENGAGE Let's Talk Research will be a non-randomised feasibility study conducted with care home residents and their chosen trusted person conducted in UK care homes aiming to establish initial feasibility of the intervention.

Participants

Participation in the study depends upon meeting the following inclusion/exclusion criteria.

Care home residents

Inclusion criteria

- An older person living in a care home who is able to:
    - nominate a trusted person
    - provide informed consent
    - engage in a guided discussion

Exclusion criteria

- Unable to attend session(s)

Trusted person

Inclusion criteria

- An individual chosen by the resident (i.e., a relative, friend, or care home staff member) who is able to:
    - provide informed consent
    - engage in a guided discussion

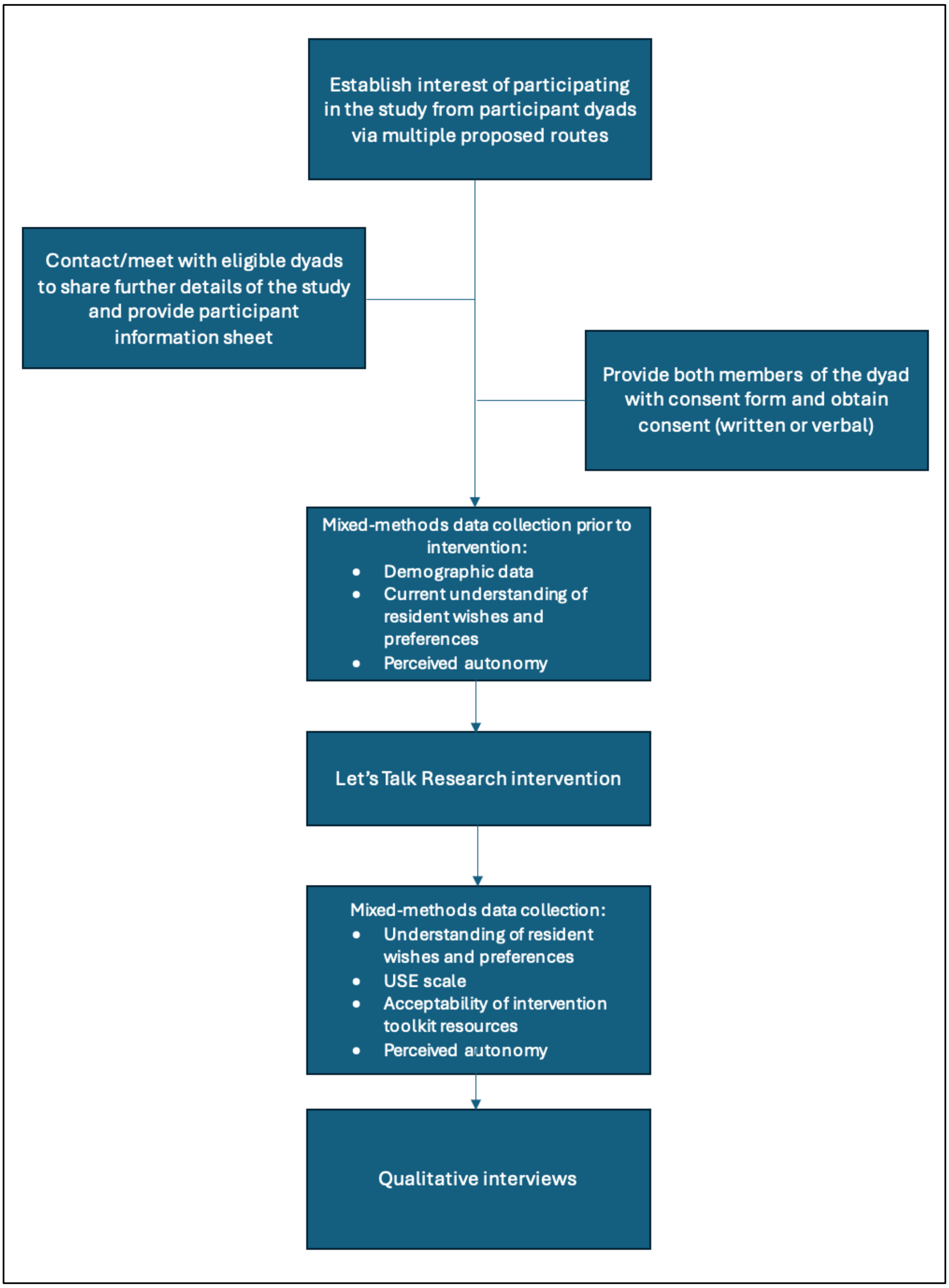
Exclusion criteria

- Unable to attend session(s)

A ‘trusted person’

In order to take part in the intervention, it is essential that a dyad is recruited. A ‘trusted person’ is someone that the care home resident chooses and is comfortable having a conversation about their research wishes and preferences with. This may be a relative, friend, or member of care home staff. Ideally, the chosen ‘trusted person' is an individual who may, in the future, make decisions on behalf of the resident should they lose capacity to consent for themselves.

Figure 7.10 Proposed study flow chart



Recruitment

A recruitment strategy will target potential participants (residents and/or their trusted person) a number of routes, primarily through: 1) relevant organisations and networks; 2) online sources; and 3) community sources.

Relevant organisations and research networks

Organisations and networks such as ENRICH, ENRICH Cymru, and ENRICH Scotland have a network of care homes who have expressed their interest in taking part in research. Recruitment advertisements will be shared to these ‘research ready’ care homes through such networks. Recruitment adverts will also be shared through relevant organisations such as CARE, AGE UK, Age Cymru, CADR, and ARC. Contact details for the research team will be included on advertisements and more detailed study information will be shared with any care homes that show interest.

Online recruitment

ENGAGE Let’s Talk Research social media accounts will be set up on Facebook and Twitter/X to share regular updates and information about getting involved in the feasibility study. Contact details of the researcher will be shared with interested parties who will then provide more information and a detailed participant information sheet with the opportunity to ask any questions.

Community recruitment

Contact details, including email addresses and phone numbers, of care homes will be accessed online through council websites and the researcher will contact the home manager to share information about the study and assess interest in taking part. When granted access, the researcher will visit care homes to discuss opportunities with residents and their relatives at coffee mornings and events happening in the homes. Potential participants will have the opportunity to ask questions and receive more detailed information, including a participant information sheet, at these events.

Sample size

A participant sample of 5-10 dyads is targeted for recruitment. Since the intervention will only consist of one stage, retention is not likely to pose an issue. This sample size of dyads will provide sufficient evidence to estimate the initial feasibility of the intervention.

Progression criteria

Proposed progression criteria are outlined in Table 7.4. These criteria have resulted from the previous steps of intervention development, as described throughout this chapter, including PPI and wider stakeholder event feedback and findings. Progression criteria will be finalised through a consultation with the ENGAGE study PPI group.

Table 7.4 Proposed progression criteria from feasibility study to implementation study

Progression criterion	**Method of assessment**
1. Is it feasible to deliver the intervention to care home residents and their trusted person?	Participant feedback via questionnaire Participant feedback via interview
2. Is the intervention acceptable to participants?	Participant feedback via questionnaire Participant feedback via interview
3. Are participants willing to take part in a discussion about residents' research participation wishes and preferences?	Completion of discussion Participant feedback via questionnaire Participant feedback via interview
4. Are the toolkit resources appropriate for their use and acceptable to participants?	Completion of discussion Participant feedback via questionnaire Participant feedback via interview

Progression criterion	Method of assessment
5. Are the routes of recruitment appropriate, fruitful, and effective to achieve a proposed sample size for an implementation study?	Recruitment rates
6. Have identified potential barriers been considered and are procedures in place to overcome these challenges?	Process evaluation with SWOT (Strengths, Weaknesses, Opportunities, and Threat) analysis Action plan
7. Does the proposed data collection effectively collect data required to move on to an implementation study?	
8. Are the required costs feasible?	Identify required costs

Outcome measures

Proposed outcome measures are presented in Table 7.5. It is likely that the measures will be primarily completed face-to-face in the care home setting after dyads have carried out their discussions. However, should they wish, participants will have the opportunity to complete the measures at a later time, virtually (e.g., via Zoom).

Primary outcomes

In order to understand the current state of understanding of residents' research participation wishes and preferences within the dyads, a brief questionnaire will be completed separately both before and after the intervention is carried out to see if views are 1) initially matched; and 2) the intervention improves match.

The Usability, Satisfaction, and Ease of use (USE) questionnaire [385] will be completed in order to assess participants' views about the usability of the intervention toolkit resources, as well as their satisfaction with the resources.

Additionally, a Likert scale will be created to measure participants' views on the acceptability and preferences on the intervention toolkit resources in order to gain further understanding and refine the intervention further should it be appropriate.

Secondary

Perceived autonomy will be measured both before and after completing the intervention using an adapted version of the Basic Psychological Needs Satisfaction and Frustration Scale [386]. This short-form scale has been used before in previous studies [387] including three items from the original scale (e.g. "I feel a sense of choice and freedom in the things I undertake") and will be completed using a Likert scale.

Table 7.5 Proposed outcome measures

	Outcome measure	**Before and/or after intervention**
Primary outcome(s)		
Understanding and beliefs about wishes and preferences	Separate brief questionnaire for both resident and trusted person	Before and after
Usability of intervention toolkit resources	Usability, Satisfaction, and Ease of use (USE) questionnaire [385]	After
Acceptability of intervention toolkit resources	Likert scale	After

	Outcome measure	**Before and/or after intervention**
Secondary outcome(s)		
Perceived autonomy	Short form of the Basic Psychological Needs Satisfaction and Frustration Scale [386] Three items rated on a Likert scale	Before and after

Process evaluation measures

Various elements of process evaluation ensure that the intervention operates to produce intended outcomes [78]. The evaluation will be conducted based on the MRC guidelines for the development and evaluation of complex interventions, including 1) context; 2) recruitment; 3) reach; 4) fidelity; and 5) mechanism of impact. Proposed process evaluation measures can be seen in Table 7.6.

Qualitative methods

Semi-structured interviews will be conducted with all participants, either separately or in dyads, following completed discussions using the intervention toolkit resources. They will be used to explore participant views about the intervention relating to its acceptability and usability, feedback on preferences and/or suggestions about how to improve the resources for their intended population and use, and views on potential barriers to the successful use of the intervention. If interviewed in dyads, individuals may be less likely to share diverging views. However, if interviewed separately, less support may be provided for the resident to take part in the interview. Thus, a flexible approach, based on preferences may need to be considered.

Quantitative methods

The collection of quantitative data will be achieved through the use of established measures as presented above. The understanding and beliefs and perceived autonomy questionnaires will allow data to be collected and compared showing any potential impact of the intervention on these factors. The USE questionnaire will provide information on participants' views about the useability, satisfaction, and ease of use of the intervention resources.

Table 7.6 Proposed process evaluation measures

Measure	**Example questions to be answered**	**Method**
Context	Where did the discussions take place?	Qualitative interviews Quantitative analysis
Recruitment	What are the difficulties in recruitment? What was the most effective method of recruitment?	Descriptive statistics Quantitative analysis Qualitative interviews
Reach	How well does the study sample represent the population of interest? To what extent did the intervention reach and influence people other than recruited participants, including helpers? What were the particular difficulties/issues that arose during the study in delivering the intervention?	Descriptive statistics Qualitative interviews
Fidelity	Was the intervention delivered as intended? When, if any, were any adaptations needed to the planned intervention?	Descriptive statistics Quantitative analysis Qualitative interviews
Mechanism of impact	Did resident and trusted person's views about residents' research participation wishes and preferences align following the intervention? Did residents' perceived autonomy increase?	Quantitative analysis Qualitative interviews

Measure	Example questions to be answered	Method
	Did the trusted person feel more informed and confident about making a decision in line with residents' wishes on their behalf in the future should they need to?	

Research costs evaluation

A costing exercise will be carried out to provide an indication of the direct research costs of the intervention, including keeping track of resources used in delivering the intervention. Costs are likely to include:

- Travel expenses
- Printing costs
- Patient and Public Involvement
- Possible incentives for participation
- Time taken to support/implement intervention

7.7 Discussion

Successful communication requires clear exchange of information between people [369]. For some, this requires reasonable adaptations and resources to ensure equity and inclusion in taking part in meaningful discussions and sharing wishes and preferences. Throughout this thesis the importance and necessity of good communication between stakeholders within the care home setting has been highlighted, specifically for the purpose of improving the engagement of care home residents in research. This chapter has reported the development process of a communication intervention to support the facilitation of an early discussion about research participation preferences for care home residents. It describes the complex development of a proto-type toolkit, suitable for facilitating a focused discussion about research between a resident and their 'trusted person', comprising of a brief conversation guide aimed at residents, a more detailed conversation guide for the ‘trusted person’ within the dyad, and a number of visual aids to support the clarifying and answering of included questions.

Contextualised to other studies that have evaluated the effectiveness of similar interventions (e.g., those related to ACP [388]), it could be anticipated that outcome measures may include those assessing quality of life, quality of communication, or even decisional conflict. More specifically related to outcome measures for ARP, drawing on consensus methods may be of interest and applicable (e.g., [389]).

As in previous stages of this thesis, stakeholder involvement during this stage of the project was invaluable. PPI consultation proved very useful in the development of the toolkit resources including their content and appropriateness, as well as in the iterative intervention refinement process. Although the stakeholder event did not run as intended, the event provided a key learning experience about what does not work in the implementation of the intervention, and confirmed a number of assumptions such as the required target population, thus proving useful nonetheless.

Further work is required to understand whether the intervention would be feasible in real world care home settings with the target population. A proposed feasibility study protocol has been included, considering both the primary data collected throughout this thesis, the important PPI feedback received, and the lessons learned through the attempt at holding a wider stakeholder event to conduct a small pilot of the intervention.

7.8 Summary

Whilst there has been considerable interest in advance care planning within health and social care settings and relevant interventions have been developed, the exploration of advance planning for research in vulnerable populations has been relatively neglected. The complex development process reported in this thesis chapter has resulted in an intervention aiming to address the difficulties in communication which serve as a barrier to the inclusion of care home residents in research. This intervention addresses the very early stages of improving care home residents' inclusion in research, by emphasising the importance of supporting residents to share their preferences. Supporting their communication and facilitating conversation crucial to improving researchers, relatives, health care professionals, and other stakeholders' understanding of what care home residents want, allowing relevant individuals to be informed should they lose capacity to consent for themselves in the future. Further piloting of the intervention is required with the intended population.

7.9 Reflections

Starting out with little knowledge about intervention development, I found this stage of my PhD the most challenging. After my initial confusing exploration of different available frameworks, I benefitted greatly from training courses including: Developing and Evaluating Complex Interventions provided by the National Centre for Research Methods (NCRM); and Methodological Innovation in Public Health Intervention Science: Development, Evaluation and Adaptation provided by the Centre for Development, Evaluation, Complexity and Implementation in Public Health Improvement (DECIPHer). After solidifying the frameworks I would use, I enjoyed working through the systematic processes. However, I found that my biggest challenge was ensuring that I had included each element proposed by the Medical Research Council's guidance and reported them in an accessible format. With so many different elements to consider, as well as the iterative nature of the process, I found it a challenge to establish a structure when writing this chapter. With continuous refinement of the intervention elements, as encouraged by the MRC guidance, I had multiple drafts of sections and figures which I had to choose between to include in the write up.

PPI was very successful during this stage of the project, as it has been throughout. Gaining feedback from a stakeholder really helped to consider the perspective of someone representing one of the intended users of the intervention.

I think perhaps my steepest learning curve during this stage of the project was carrying out the wider stakeholder event. Whilst I tried to be as clear and informative about the requirements of the event, it seemed that the most important factors were perhaps not understood by the member of care home staff I worked with to organise the event; or perhaps the. care home had an alternative agenda for the event. For example, when my supervisor and I arrived at the care home and began to interact with the residents who were brought to the dining room to take part in the event, it was clear that the majority were not able to engage in meaningful discussion as stated. Furthermore, no relatives attended the event and so we had to act as each of the residents' partner, one-by-one, to at least try to get some feedback about the resources and their appropriateness. Whilst I believe we made the best out of a situation which was not ideal, it was obvious that the resources did not get fully explored because the individuals it was intended for were not present. This event did not follow the proposed plan as intended but valuable insights were gained to help inform the next steps for this work. The residents thoroughly enjoyed chatting with us and I gained insight into what does not work, reiterating a number of initial thoughts about the implementation of the intervention.

Thinking ahead, I anticipate that general areas which may be impacted are resident autonomy and increased research participation – and I hope to understand these further following the completion of the feasibility study.

Chapter 8 - Discussion

8.1 Chapter overview

This chapter provides an overview of the work carried out as part of this doctoral thesis, including key findings and novel contributions. Implications for policy and practice are discussed, and strengths and limitations of the methodological approaches are included. This chapter also provides suggestions for further areas for research.

8.2 Aims of this PhD thesis

The aim of this thesis was to identify ways to engage and support care home residents to make informed decisions about participation in research and to develop an intervention to support residents' decisions regarding inclusion in research at a future time when they may no longer have capacity to make a decision.

Barriers and facilitators to care home residents' participation in research, including residents who are able to provide their own consent and those whose capacity to consent is impaired, have been identified. This was achieved through the completion of a scoping review of available literature and a cross-sectional survey of stakeholders' views (Chapters 2 and 3) and supported by a qualitative exploration of stakeholders' views about encouraging early discussions to elicit residents' preferences about research participation and facilitate advance planning for research participation (Chapter 4). This has contributed to a more complete understanding of stakeholders' views which has informed intervention development. Finally, the aim of this thesis was achieved through the comprehensive development of a communication intervention to help care home residents discuss their wishes and preferences about participation in research (Chapters 5, 6, and 7).

8.3 Summary and interpretation of key findings

The ENGAGE study, presented in this doctoral thesis, has focused on developing a comprehensive understanding of why care home residents are underrepresented in research through the identification of barriers and facilitators to resident inclusion in research, explored key stakeholders' views on a potential approach to overcoming the apparent complex communication barrier to resident inclusion, and began the iterative process of developing and refining a complex intervention to support residents to share their research participation wishes and preferences. The ENGAGE study has taken a step forward in the care home research field by identifying and bringing together apparent, known barriers to resident inclusion in research and providing recommendations to overcoming challenges more broadly,

as well as focusing on one particular barrier to target through the development of a complex intervention.
The scoping review undertaken as part of this project identified barriers and facilitators to the inclusion of older adults living in UK care homes in research. A number of complex factors, generally acting as either barriers or facilitators, were identified in this review including: 1) research design; 2) understanding and beliefs about research; 3) communication; 4) relationships; 5) eligibility criteria (resident and care home); 6) preference-based decisions; and 7) care home staff and environment. It was apparent that barriers to residents' inclusion were often related to factors outside of their control, seen often also in the inclusion of older adults generally in trials research [194].

The findings enabled a better understanding of common barriers and facilitators to the inclusion of care home residents in research, as well as contributing to an output presenting recommendations to researchers of ways these factors can be modified to improve research within the field. The chapter ended with the suggestion that further research is required in order to explore the interaction between the direct and indirect barriers and facilitators to care home resident inclusion in research and identify interventions that target the modifiable barriers and facilitators to improve inclusion.

Following the scoping review a cross-sectional survey study was carried out to explore stakeholders' views about opportunities for older adults living in UK care homes to participate in research. The survey design was largely informed by the findings of the scoping review presented in Chapter 1. In this study, a range of stakeholders identified what they believed to be the greatest barriers and facilitators to the inclusion of care home residents in research. The greatest barriers identified by stakeholders included the lack of awareness about research opportunities and difficulties in communication, reported often in the literature [125, 166, 180], which offer potential targets for intervention when aiming to improve inclusion. The most impactful facilitators identified by stakeholders were positive staff engagement and flexibility of researchers within the care home around organisation and routines which identified important issues to target when considering ways to improve resident inclusion in research. After identifying the greatest barriers and facilitators to inclusion, stakeholders also suggested ways to address them. The sharing of research opportunities by researchers coming into homes personally was most favoured and emphasises the importance stakeholders place on relationship building. However, discordance between stakeholders' views was also apparent in this study, particularly between residents and other stakeholders, which is also often seen in the literature relating to perceived autonomy and control, wellbeing, and communication [241-243]. This chapter ends with the interpretation that communication between stakeholders is currently not effective and would benefit from strategies or interventions to improve how opportunities and preferences about research are communicated.

Informed by the findings of the previous two chapters, I further investigated the areas of importance to stakeholders in tackling the inclusion of care home residents in research, as well as their views on advance planning for research participation. This was achieved through a qualitative interview study exploring stakeholders' views about advance planning for care home residents' research participation, influenced by the background concept potentially applying established principles to targeting the issue of focus of this project. Three important themes were identified through the collection and analysis of primary data at this stage of the project: 1) We're of no value to research; 2) Research is difficult; and 3) Advance research planning: good in theory, difficult in practice. Stakeholders identified a number of barriers to including care home residents in research, highlighting factors previously identified within this thesis, and also including being unaware of residents' preferences about research. The lack of communication about residents' research participation because of such conversations being uncommon emphasised the need for early intervention. This chapter concluded with the statement that future interventions to facilitate communication are needed to support discussions and decision-making with care home residents about wishes and preferences for future research participation. The decision to focus on communication going forward was confirmed at this stage. The publication of a research article based on this thesis chapter was accompanied by an editorial emphasising the importance of this research.

Moving forward, I carried out a critical analysis of theories relevant to this thesis and the planned intervention. The exploration and analysis undertaken in this chapter was key to understanding and making sense of the findings that arose from primary data collection throughout this thesis. The application of theory to these findings also supported the plan to develop a theory-based and informed complex intervention.

A review of candidate interventions and resources to support decision-making about care and life choices for older was then carried out. The findings from the previous chapters identified the need for an intervention and this chapter begins the pre-work for such development. Apparent from the findings of this review was that existing interventions have been successful in supporting their target population. Certain features of the reviewed interventions and resources, such as conversation guides [310, 343] and visual aids [347, 382], have the potential to be adapted to care home residents which was able to be considered in the following intervention development process. This chapter ended with the proposal of adapting relevant elements of other interventions and resources to the development of the intervention for this project.

Informed by the previous work reported in this thesis, Chapter 7 synthesises previous chapters to present the process of complex intervention development which has produced a communication intervention to support care home residents to share their research participation wishes and preferences. Primarily following the 'intervention development and adaptation' stage of the MRC guidance [78] for complex intervention development and evaluation, this chapter sets out the core elements required for rigorous intervention adaptation. This comprised of an iterative process that included the consideration of the implementation context, development of a programme theory and logic model, engagement with stakeholders, and refinement of the intervention. Further development of the intervention is discussed, and this chapter concludes with a proposed feasibility study protocol.

Upon reflection I believe that I have used a multi-methods approach within this project, rather than the originally suggested mixed-methods approach. This is because I used multiple methods within the project separately, analysed them separately, and triangulated the findings. A mixed-methods approach would have required the integration of qualitative and quantitative methods both during data collection and analysis. The triangulation of findings undertaken during this project involved comparing the findings from different methods (i.e., scoping review, survey study, interview study, review of existing interventions) to support the validity and robustness of the discussion and conclusions drawn within this thesis.

8.4 Novel contributions of this work

This doctoral thesis presents a number of novel findings, some of which have been published as articles in journals and disseminated through blog posts, poster and oral presentations at academic conferences, and within relevant networks and organisations ENRICH, Age UK, Centre for Trials Research at Cardiff University, PRIME Wales, and Health and Care Research Wales.

Chapter 2 presents a scoping review which is the first to identify barriers and facilitators to care home residents' inclusion in research. It provides a comprehensive account of the challenges faced by researchers when trying to include care home residents in research and, informed by the findings, a novel set of recommendations to help researchers overcome such challenges was created and disseminated via an infographic (see Chapter 2, Figure 2.2). A research article based on this chapter has been published in a peer-reviewed journal, BMC Geriatrics, and cited at least 12 times to date. Further dissemination of this review has included blog posts, poster and oral presentations at academic conferences, and leading a meeting with Age UK and partners.

The cross-sectional survey study reported in **Chapter 3** provides the first exploration of stakeholders' views on care home residents' research participation, providing insight into views about the impact of identified barriers and facilitators to inclusion, decision-making in the care home setting, and what can be done to improve resident inclusion. Alongside the findings of this study, the collaborative development of the survey questions with a PPI group provides support to the scoping review findings reported in **Chapter 2**. A research article based on the work carried out in this chapter has been published in a peer-reviewed journal, Nursing and Residential

Care journal. Work from this chapter has been shared at a number of academic conferences, both via posters and oral presentations.

The novel work presented in **Chapter 4** has also proved to be of interest to the research community. A research article based on a version of this study was recently published in the peer-reviewed journal, Age and Ageing, and was accompanied by an editorial [390]. The editorial focused on facilitating equitable research access for people living in care homes and includes discussion around the tension between stakeholders' beliefs about the potential distress advance research planning conversations could have for residents. Chapter 4 offers a novel exploration and in-depth analysis of stakeholders' views about advance planning for care home residents' research participation. Informed by the findings, a set of recommendations for each stakeholder group were developed to enhance opportunities for residents to express their research participation wishes and preferences. Further, the findings and outputs from this chapter have also been shared at a number of academic conferences, both via posters and oral presentations.

Chapter 5 presents a critical analysis of theories relevant to care home residents' underrepresentation in research. The application of theory to primary data collected in studies undertaken as part of this thesis offers understanding of the findings and can inform work to overcome apparent challenges. The application of theory to intervention development was also considered in this chapter.

Chapter 6 offers a novel brief review of existing interventions and resources to support decision-making about care and life choices for older adults, relevant to the current project, to inform the development of a complex intervention.

Chapter 7 presents the triangulation of all the previous empirical and review work undertaken within this thesis and reports the development of a novel complex communication intervention aiming to support care home residents to share their research participation wishes and preferences.

8.5 Implications for practice and further research

8.5.1 Implications for practice

The work presented in this thesis highlights the complexity of including care home residents in research and the current challenges faced. The findings will be relevant to researchers who wish to include care home residents in their research, offering common identified barriers to inclusion and resulting recommendations for overcoming such challenges. Further, the findings offer insight into the views around resident research participation of stakeholders including residents, relatives, care home staff, other HSCPs, and researchers, which can be taken into consideration when designing and conducting research with care home residents. The collaboration with a PPI group has ensured that the work considered the real-world application of studies and outcomes, informed by the real experiences and expertise of stakeholders.

Furthermore, the development of recommendations for all stakeholders about how to enhance opportunities for residents to express their research participation wishes and preferences offers information to a wider audience including those who can make a difference in supporting care home residents' inclusion. Residents, relatives, care home staff, HSCPs, researchers, research ethics committees, funders, and regulators can all play a role in ensuring care home residents have the best chance of being included in research, positively impact their representation, and potentially influence future health and social care for care home residents.

The complex intervention developed in this project has the potential to impact the lives of residents and their close family. The intervention will be of benefit to researchers aiming to recruit care home residents and ultimately the future inclusion of care home residents who are often overlooked because of cognitive impairment and other health issues which makes their participation challenging. Should conversations around residents' research participation wishes and preferences be facilitated early enough, using this supportive communication intervention, residents will receive the opportunity to have their voices heard by someone (i.e. a relative or other ‘trusted person’) who may go on to take a role of personal consultee or advocate in the future. This advocate or trusted person may be presented with the decision to provide consent should opportunities arise at a time where the resident is no longer able to provide consent for themselves. Thus, the intervention may facilitate an informed decision based on documented wishes and preferences of the resident, also removing decisional burden for the relative or trusted person.

Additionally, in relation to the wider context, the work presented in this thesis aligns with the apparent growing requirement to ensure research is inclusive of under-served populations, including from funders such as the National Institute for Health and Care Research (NIHR) [27], and recent World Health Organisation (WHO) Guidance for Best Practices in Clinical Trials [28]. The present work complies with the notion that facilitating more inclusive research for care home residents may help to address “evidence-biased” medicine, as has been identified in work investigating the impact of research regulation in vulnerable populations [29]. The work presented in this thesis also addresses the priority area of equality, diversity and inclusion and is aligned with wider Welsh Government policy. This project also supports the vision of ‘A Healthier Wales’ which aims for everyone in Wales to have longer, healthier and happier lives and to reduce inequalities and improve population health outcomes [30]. This is captured in the intention to create ‘an equitable system which achieves equal health outcomes for all’.

8.5.2 Further areas for research

First, there has been consistent identification of an apparent underlying issue surrounding the lack of research infrastructure within the care home context. This impedes the ability to both include care home residents in research, and conduct research in care homes generally, it is essential that improvements need to be made here. The development and support of organisations, such as ENRICH, which enable research in care homes are of huge importance in creating a research network that supports ongoing important research with, and to the benefit of, this population. Further work to strengthen research infrastructure within the care home context is crucial in influencing the future sustainability of care home research.

In Chapter 7, I have proposed a protocol for a feasibility study which will be an essential next step to assess the intervention. In line with the MRC guidance for complex intervention development and evaluation [78], a feasibility study will provide an opportunity to explore the feasibility of the intervention and evaluation design and answer the question of whether implementation can be undertaken, whether it should proceed, and how to progress to evaluation [78]. I have been successful in my application for Health and Care Research Wales' Next Steps Award to undertake this proposed work.

Additionally, there are other opportunities for further research which could be taken forward following the work presented in this thesis. The work presented in Chapter 2 could benefit from further investigation focusing on the differences of key barriers and facilitators to resident inclusion in research between different types of care homes, i.e., those who only provide residential care, homes that specialise in dementia care, and those who only provide nursing care.

Furthermore, as initially identified in Chapter 2 and emphasised throughout later chapters, there are a number of other existing barriers to the inclusion of care home residents in research. Whilst poor communication has been highlighted as the target for intervention development within this thesis, it may be possible that other barriers identified at different levels within wider systems could be useful in engaging care home residents in research. Referring back to the complex systems approach, included in Chapter 7, it may be the case that targeting a barrier identified between alternative systems may be impactful. For example, I have identified that relatives often have influence over which opportunities residents are exposed to and choose to take part in. The development of a tool or intervention to improve the relationship between relatives and researchers may encourage relatives to act as collaborative partners in the research development and recruitment processes. Such a target may overcome other barriers that have been identified such as gatekeeping and getting access to residents to share opportunities.

In addition, the influence of wider system levels has been considered throughout this thesis and remains important because of the complexity of the care home setting and its stakeholders. Future research may benefit from a focus on more in-depth work with stakeholders around these wider system influences.

8.6 Methodological strengths and limitations

8.6.1 Scoping review

As stated in Chapter 2, the chosen scoping review method was fit for the purpose of this project. As a relatively unexplored research area, the identification of the amount and nature of available literature was essential, as well as basic concepts, key sources, and research gaps. For these reasons, the chosen methodology provided a beneficial broad overview and was more appropriate than alternative methods, such as a systematic review, which focuses on quality assessment and meta-analysis. The structured yet versatile nature of the framework was easily adapted to this project and allowed for comprehensive literature mapping. Throughout this stage of the project, the scoping review framework helped to define and clarify key concepts, theories, and gaps in the literature providing the thesis with a clear and strong foundation going forward. Carrying out a literature review which was to inform the following stages of the project using a structured framework provided confidence that key concepts within the available literature had been identified.

Whilst appropriate for the nature of this project, scoping review methodology is not without its limitations. The subjective nature of defining inclusion and exclusion criteria, and selecting literature to include based on these, has the potential to introduce bias. In this project, screening was undertaken by the researcher following the joint screening of a random selection of articles with a supervisor to ensure robust application of the eligibility criteria.

8.6.2 Survey study

The cross-sectional survey, reported in Chapter 3, provided an efficient and useful design to identify an overview of stakeholders' views. The development of the survey, informed by the previous chapter findings, also meant that stakeholders were able to voice support for, or clarify, the review findings and provide a valuable real-world perspective based on their own experiences. Further, this method allowed for comparisons to be made between different stakeholder groups based upon the demographic data collected.

However, cross-sectional survey designs are limited by potential response bias. In this case, care home residents provided the least responses, whilst care home staff and relatives were more represented. This may result in overall findings which lead to biased conclusions. The use of content analysis provided a systematic and objective approach to the analysis of data gathered through the cross-sectional survey. This method was able to expand on the more restrictive tick box, or pre-coded, data items. This allowed for participants to expand on their ideas and concerns in their own words and flag issues that the researcher may not have thought about.

8.6.3 Interview study

Following the use of survey methodology to explore stakeholders' views, conducting semi-structured interviews to elaborate and gain more depth was a strength of the project method progression. The flexibility provided by this method suited the different abilities between stakeholder groups and allowed adaptations to be made by the interviewer whilst keeping a focus on the topic of interest. Follow up questions to clarify responses from participants and to encourage elaboration of answers allowed for deeper exploration and helped to capture complexities of participants' experiences and views. In all, the use of semi-structured interviews supported the gathering of a comprehensive understanding of stakeholders' views.

Semi-structured interviews can, however, be particularly time-consuming. Additionally, it can be noted that I did not enter this stage of the project as a particularly experienced interviewer. The notion of interviewer bias, including delivery of the questions, may also be important to consider as a potential limitation of this method. However, in an attempt to overcome some of these known limitations, I piloted an interview with an experienced colleague to receive feedback about my question delivery and general interviewing techniques which provided me with some confidence going forward.

The use of Braun and Clarke's [80] thematic analysis as a technique to analyse the data collected through semi-structured interviews provides a number of strengths to this project. Firstly, its accessibility and the vast information available about how to conduct thematic analysis was suitable for me, as a researcher with only some previous experience. This supported the deep exploration of data alongside identifying complex themes, helping me to understand the experiences and views that participations shared. The nature of thematic analysis supports one of the main aims of this thesis also, which is to prioritise and emphasise the voices of care home residents, as well as allowing other stakeholders to contribute their views and experiences.

As a relatively inexperienced thematic analyst, it was possible that my interpretation of the complex data may have lacked deeper meaning. However, this stage included joint transcript coding, separate coding of a random selection of transcripts by a supervisor, and thorough discussion of the codebook that I developed. For these reasons, the project benefitted from the use of thematic analysis and expertise of the project supervisors and enabled me to develop skills and experience in the use of this data analysis method.

8.6.4 Intervention adaptation

The intervention adaptation stage of this thesis, reported in Chapter 7, hugely benefitted from the use of an established framework for intervention development and evaluation [78], and the ADAPT guidance [84]. Firstly, strengths of using the comprehensive MCR guidance include its structured approach to intervention development, emphasis on theory, flexibility across contexts, and inclusion of feasibility and pilot testing. Its systematic process provides a clear route for researchers to follow, which helps to reduce the risk of poorly designed interventions, and supports the creation of interventions that are grounded in theory and empirically tested [378]. Further, the emphasis placed on having a strong theoretical foundation by the guidance, and identification of key mechanisms of action to guide intervention design and evaluation propose further strengths for the use of the MRC guidance.

On the contrary, the MRC guidance is not without its limitations, which can include the complexity of its application to practice. Research in behaviour change and implementation science has suggested that the requirement for detailed theoretical work, primary research, and extensive piloting can be both resource intensive and time consuming which can make it challenging to apply in resource-constrained, complex settings [391]. It has been apparent throughout this thesis that care home settings are both resource-constrained and experience time challenges and so attempts to implement the intervention discussed in this thesis will need to carefully consider these factors.

Furthermore, both strengths and limitations of the ADAPT guidance must be considered. As a key framework in public health and implementation science, the ADAPT guidance boasts its strength of ensuring contextual relevance and flexibility. It places emphasis on considering settings, cultural nuances, and resource availability when adapting an intervention which allows them to be more relevant and effective in diverse settings, thus improving the chances of success in specific environments [84]. Further, the ADAPT guidance provides a systematic process for assessing, planning, and implementing adaptations which helps researchers to clearly navigate a complex process [392]. The ADAPT guidance also stresses the importance of stakeholder involvement which is also in line with the underlying aims and objectives of the ENGAGE study.

On the other hand, whilst comprehensive and structured, the ADAPT guidance has been criticised for its risks in leading to over-adaptation. The risk of researchers, or practitioners, adapting too many components of established interventions to a new context may lead to interventions that drift too far from original models and thus lose effectiveness. Maintaining fidelity to core elements is crucial for achieving the desired outcomes of an intervention, and ensuring a balance between adaptation and fidelity can present a challenge for researchers [392]. Lastly, the primary focus of the guidance on adapting interventions at the individual or program level may result in an intervention that does not fully consider, or account for, wider system-level influences, posing a limitation. However, in this thesis, a socio-ecological systems approach for intervention development was considered as wider system influences were apparent, and discussed, throughout previous chapters.

8.7 Patient and Public Involvement

As stated throughout, PPI has been truly invaluable to this thesis and I have been grateful at each stage of the project to receive suggestions and feedback from those with lived experience, as well as being challenged to ensure I was able to explain the processes followed and choices made. The PPI group was established at the beginning of the project, comprising of one member of care home staff, one relative, and one relative who is also an experienced researcher. During one of the later stages of the project, I was able to recruit a care home resident to the PPI group too. The contributions of PPI which have benefitted the project are detailed in Table 8.1.

Table 8.1 The contributions of PPI throughout different stages of this thesis

Chapter no.	**Contributions**
Chapter 2	A consultation stage was included in this stage of the project in which PPI members were presented with, discussed, and provided feedback on the findings of the scoping review. Changes were made to the reporting of my findings based on PPI feedback including clarity in definitions, use of certain vocabulary, presentation of information in visualisations, and suggestions for further inquiry. Because of the feedback received by the PPI group, the reporting of findings in this stage of the project were more accessible, clearer, and appropriate for the reader.

Chapter no.	Contributions
Chapter 3	The PPI group were involved in the development of the survey in this stage of the project. Members provided feedback during our meeting, ensuring that the survey content was clear, easy to understand, appropriate, and accessible. Changes were subsequently made to the design and content thanks to the input of PPI members. Such changes included the use of vocabulary and phrasing, formatting of questions, and the inclusion of prompts and additional information for clarity.
Chapter 4	Two separate sessions were held with PPI members during this stage of the project to discuss the findings of the interview study. From these discussions, PPI members offered clarity and further insight into the themes identified within the data. PPI members were able to support and strengthen the initial theme development and shared their own important views and experiences relating to the themes and quotes shared from interviews.
Chapter 7	Although not directly involved in choosing the model used, PPI was an integral part of the intervention development process. During this stage of the project, the development and refinement of the intervention resources particularly benefitted from the inclusion of PPI. Additional questions were included in the conversation guide, alternative visual aids were suggested and included, and suggestions were made about the formatting and presentation of the resources to the target population.

8.8 Concluding remarks

Using both quantitative and qualitative methods, I found a number of barriers to the inclusion of care home residents in research through this project. I decided to target the apparent complex communication barrier to inclusion in this project and in doing so developed an intervention to support care home residents to communicate their research participation wishes and preferences, including the adaptation of an existing intervention, to achieve this. The intervention presents an early opportunity for discussion facilitation around residents wishes and preferences so that they are documented and can be honoured should they lose capacity to consent to research participation in the future, supporting both potential personal consultees and researchers during future recruitment.

The original research proposal submitted for funding by my supervisors was primarily focussed on addressing challenges to conducting research in care homes and developing an intervention to support residents' decision-making about research participation. This focus was in part due to issues of a lack of high-quality evidence to improve standards of care and quality of life for residents and challenges of including people with impaired capacity to consent in research. However, during my thesis I was aware of additional important priorities such as ACP. Furthermore, the primary data from studies carried out and reported in chapters 2-4 indicated that the one of the most important focuses for interventions should be on communication and targeting the facilitation of early discussions with residents about research participation wishes and preferences. This is to ensure that residents who may lose capacity in the future have the chance to share their wishes and preferences when able, and to have their voices heard and wishes honoured later.

Care home residents are an underrepresented population in research. This underrepresentation results in poor generalisability of research findings to care home populations that could improve their complex care and quality of life. However, through taking on board the work presented in this thesis, stakeholders (particularly the research community) can work to improve their own practice ensuring that they are providing the optimal conditions to prevent the unnecessary exclusion of care home residents in research.

The novel work, recommendations, and intervention development combined to create this thesis presents a true focus on inclusivity. Care home residents are one of the most vulnerable populations in our society who, despite requiring the additional help provided by residing in a care home, have the same right to be included in research as every other individual in society. Disparities between adverse outcomes, including mortality, of care home residents and the other populations have been highlighted because of horrific outcomes, such as those identified during the COVID-19 pandemic. It is not acceptable to exclude members of society from participating in research because of difficulties in communication, practical difficulties, or resource challenges within the research community or care home setting, and this thesis hopes to highlight ways that such barriers to resident inclusion can be overcome.

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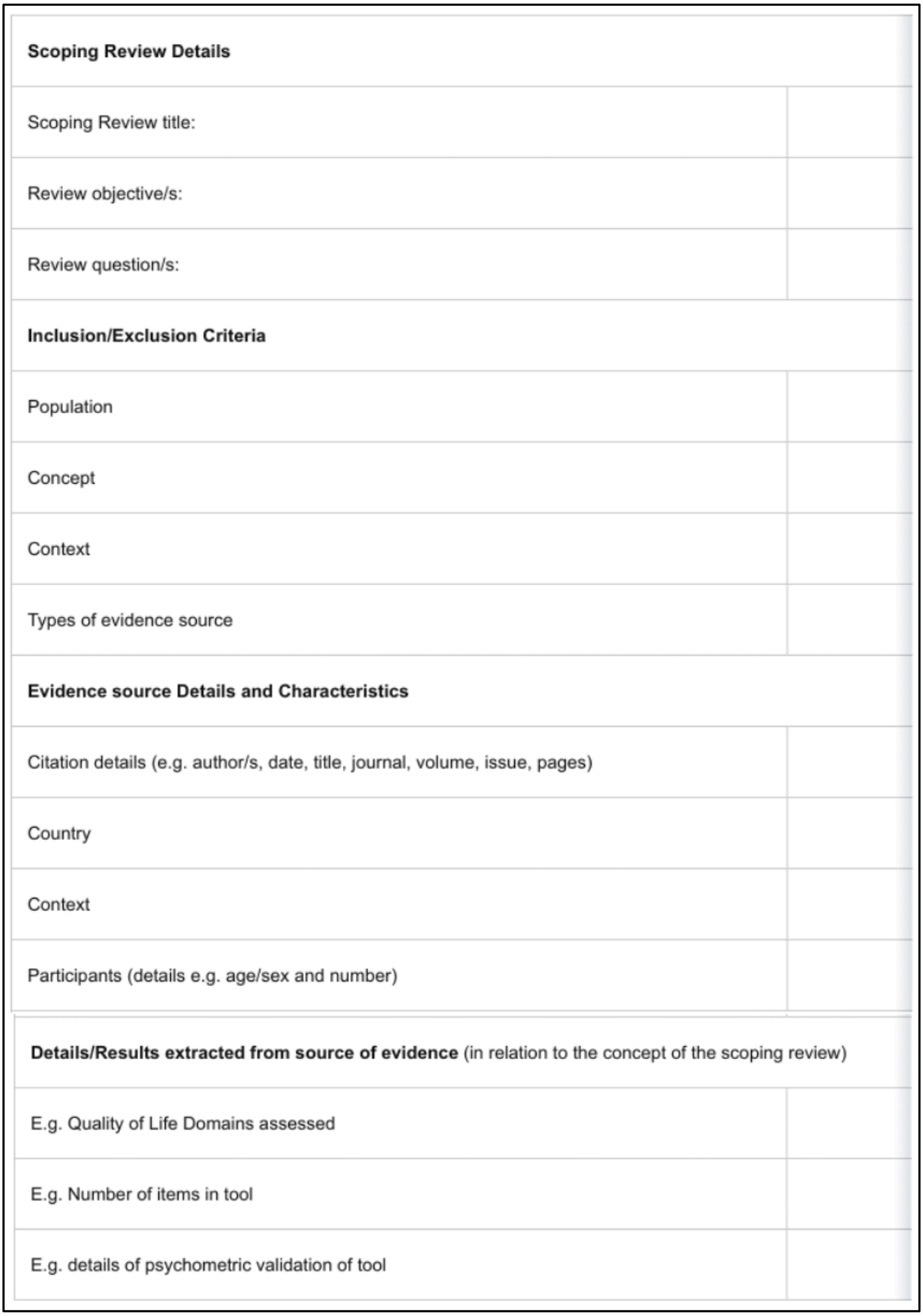
Appendices

Appendix 2.1 – Joanna Briggs Institute data charting table



Scoping Review Details	
Scoping Review title:	
Review objective/s:	
Review question/s:	
Inclusion/Exclusion Criteria	
Population	
Concept	
Context	
Types of evidence source	
Evidence source Details and Characteristics	
Citation details (e.g. author/s, date, title, journal, volume, issue, pages)	
Country	
Context	
Participants (details e.g. age/sex and number)	
Details/Results extracted from source of evidence (in relation to the concept of the scoping review)	
E.g. Quality of Life Domains assessed	
E.g. Number of items in tool	
E.g. details of psychometric validation of tool	

PART 2 - ABOUT YOU

How would you describe yourself for the purpose of this study?

☐ Care home resident
☐ Relative of care home resident
☐ Friend of resident
☐ Care home staff member (please state role)

____

☐ Other health or social care professional who works with care homes (please state role)

____

☐ Researcher

Where is the care home you/your relative reside or work in/with?

☐ Wales (please state area)

____

☐ England
☐ Scotland
☐ Northern Ireland

How long have you/they been living in a care home, or working in/with care homes?

____

How old are you?

☐ 18-35 years
☐ 36-55 years
☐ 56-75 years
☐ 76-95 years
☐ 95+ years

4 of 7

PART 3 - YOUR VIEWS ABOUT CURRENT OPPORTUNITIES FOR RESIDENTS TO TAKE PART IN RESEARCH

How are opportunities to take part in research currently shared with residents and their families? Please tick any that apply.

☐ Care home staff

☐ Other health and social care professionals

☐ Social media

☐ Posters or information sheets

☐ Researchers

☐ Other (please specify)

____

How are decisions about residents taking part in research usually made? Please tick any that apply.

☐ Resident makes own decision

☐ Care home staff made decisions

☐ Family/friends make decision on residents' behalf

☐ Proxy/personal consultee or representative make decisions

☐ Other (please specify)

____

How do you think opportunities to take part in research could be improved for residents? Please tick any that apply.

☐ Researchers visit care homes and share opportunities

☐ Care home staff share opportunities regularly

☐ Multiple formats of sharing research opportunities (such as posters, leaflets, talks)

☐ The care home actively seeking to take part in research

☐ Other (please specify)

____

PART 4 - YOUR VIEWS ABOUT WHAT HELPS OR PREVENTS RESIDENTS BEING INCLUDED IN RESEARCH

Which of these do you consider to be the greatest barrier to residents taking part in research? Please rank barriers in order from greatest to least impactful (1 being the greatest factor and 5 being the least).

RANK 1-5

- ☐ Strict inclusion and exclusion criteria (requirements for participation being too strict)
- ☐ Difficulties with resident communication needs
- ☐ Lack of awareness about research opportunities
- ☐ Residents' feelings of not being heard or valued
- ☐ Understanding or attitudes about research

Which of these do you consider to be the greatest enabler to residents taking part in research? Please rank enablers in order from greatest to least impactful (1 being the greatest factor and 5 being the least).

RANK 1-5

- ☐ Positive staff engagement with research
- ☐ Changing communication style depending on participant needs
- ☐ Flexibility of researchers within the care home around organisation and routines
- ☐ Better understanding and positive attitudes about research
- ☐ Being part of a care home that has previously been involved in research and is registered as 'research ready'

PART 5 - YOUR VIEWS ABOUT HOW TO SUPPORT DECISIONS ABOUT TAKING PART IN RESEARCH

How can information about research be better communicated to residents/families to help make a decision about participating in research? Please tick any that apply.

☐ Present information in a way that is personalised and relevant to each resident/family member

☐ Clear, concise format – provide choice of information type

☐ Developing relationships between researchers, care home residents, family members, and staff

☐ Staff engagement and support

☐ Care home becoming a 'research ready' care home

☐ Give residents time and encouragement to make decisions

☐ Include family members from the very start

☐ Flexibility and understanding of researchers

☐ Provide a personalised decision-making process to the needs of each potential participant

☐ Other (please state)

____

How can residents be supported to express their views about taking part in research in the future should they not be able to make their own decision about taking part at that time? Please tick any that apply.

☐ Talking to residents about what their preferences would be about taking part in research

☐ Using tools such as communication aids (e.g., picture cards) to help residents express their views

☐ Other (please specify)

____

Would you be interested in being contacted with an opportunity to take part in the next stage of the project?

☐ Yes (Please provide an email address)

____

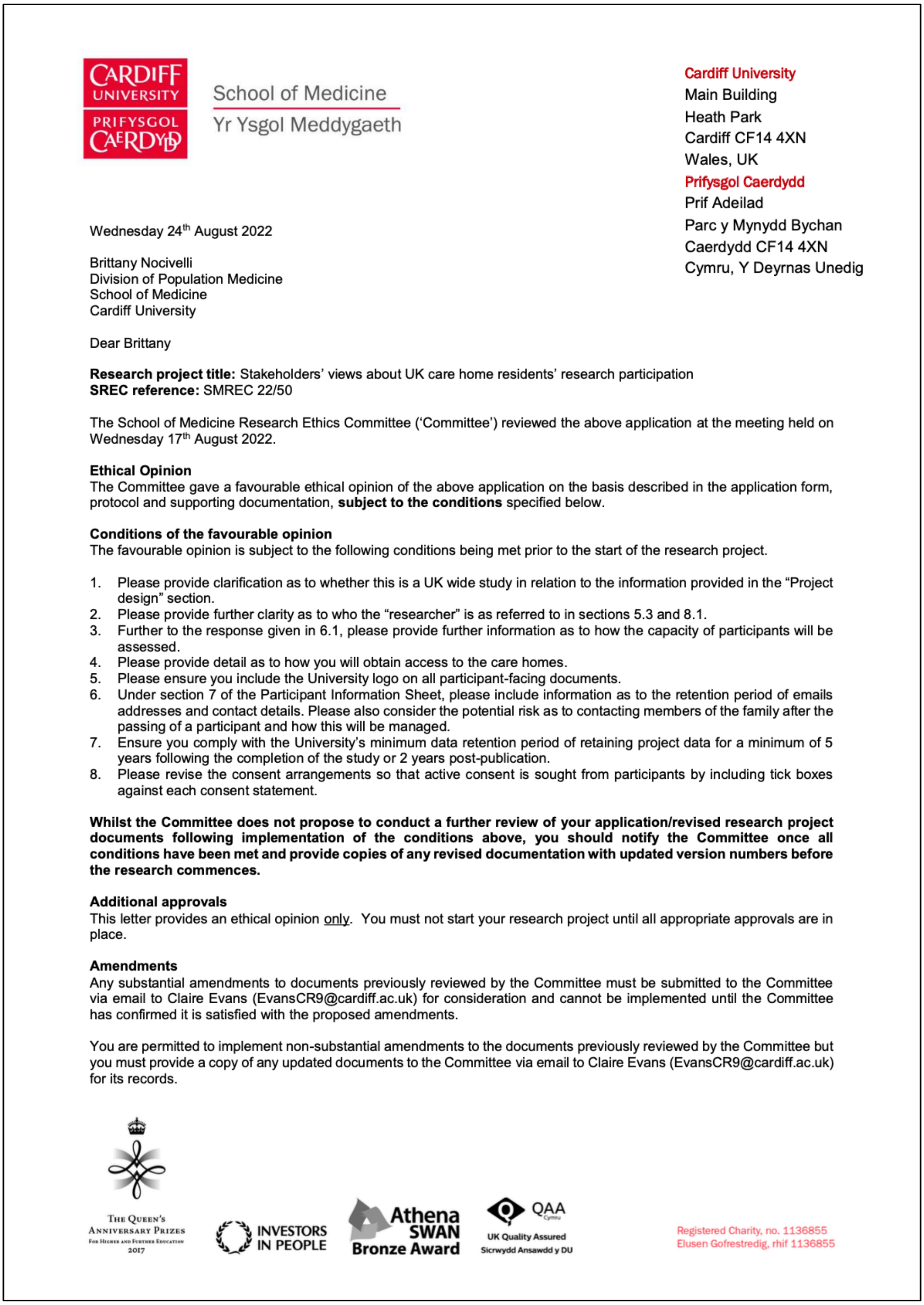
☐ No

End of survey

Thank you very much for taking part in this survey. Should you have any questions relating to this research project, you may contact us during normal working hours:

Brittany Nocivelli
nocivellibe@cardiff.ac.uk
02920 687185

Appendix 3.2 Survey study Research Ethics Committee approval letter



CARDIFF UNIVERSITY
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School of Medicine
Yr Ysgol Meddygaeth

Cardiff University
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Heath Park
Cardiff CF14 4XN
Wales, UK
Prifysgol Caerdydd
Prif Adeilad
Parc y Mynydd Bychan
Caerdydd CF14 4XN
Cymru, Y Deyrnas Unedig

Wednesday 24th August 2022

Brittany Nocivelli
Division of Population Medicine
School of Medicine
Cardiff University

Dear Brittany

Research project title: Stakeholders' views about UK care home residents' research participation
SREC reference: SMREC 22/50

The School of Medicine Research Ethics Committee ('Committee') reviewed the above application at the meeting held on Wednesday 17th August 2022.

Ethical Opinion
The Committee gave a favourable ethical opinion of the above application on the basis described in the application form, protocol and supporting documentation, **subject to the conditions** specified below.

Conditions of the favourable opinion
The favourable opinion is subject to the following conditions being met prior to the start of the research project.

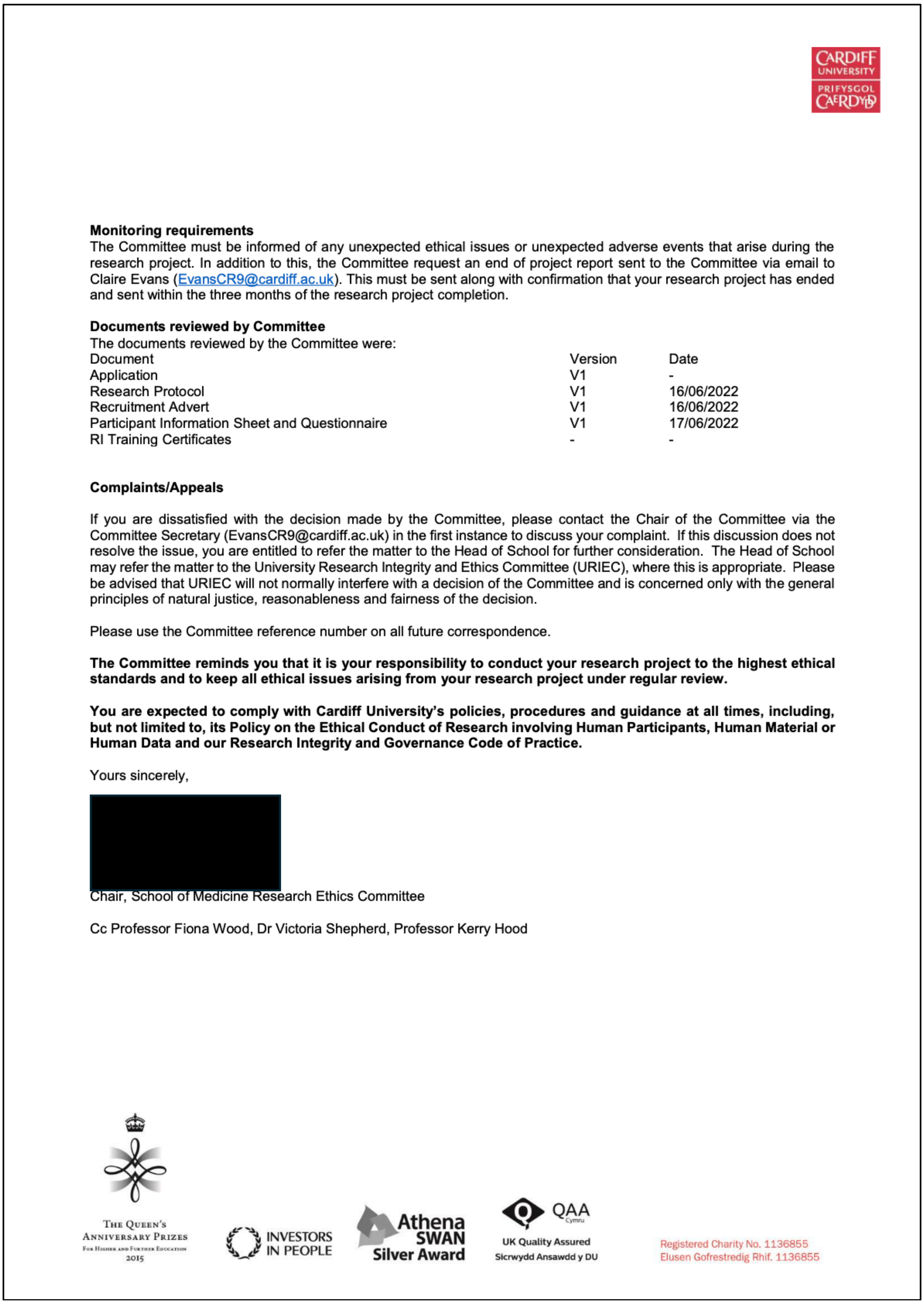
1. Please provide clarification as to whether this is a UK wide study in relation to the information provided in the "Project design" section.
2. Please provide further clarity as to who the "researcher" is as referred to in sections 5.3 and 8.1.
3. Further to the response given in 6.1, please provide further information as to how the capacity of participants will be assessed.
4. Please provide detail as to how you will obtain access to the care homes.
5. Please ensure you include the University logo on all participant-facing documents.
6. Under section 7 of the Participant Information Sheet, please include information as to the retention period of emails addresses and contact details. Please also consider the potential risk as to contacting members of the family after the passing of a participant and how this will be managed.
7. Ensure you comply with the University's minimum data retention period of retaining project data for a minimum of 5 years following the completion of the study or 2 years post-publication.
8. Please revise the consent arrangements so that active consent is sought from participants by including tick boxes against each consent statement.

Whilst the Committee does not propose to conduct a further review of your application/revised research project documents following implementation of the conditions above, you should notify the Committee once all conditions have been met and provide copies of any revised documentation with updated version numbers before the research commences.

Additional approvals
This letter provides an ethical opinion only. You must not start your research project until all appropriate approvals are in place.

Amendments
Any substantial amendments to documents previously reviewed by the Committee must be submitted to the Committee via email to Claire Evans (EvansCR9@cardiff.ac.uk) for consideration and cannot be implemented until the Committee has confirmed it is satisfied with the proposed amendments.

You are permitted to implement non-substantial amendments to the documents previously reviewed by the Committee but you must provide a copy of any updated documents to the Committee via email to Claire Evans (EvansCR9@cardiff.ac.uk) for its records.



Monitoring requirements
The Committee must be informed of any unexpected ethical issues or unexpected adverse events that arise during the research project. In addition to this, the Committee request an end of project report sent to the Committee via email to Claire Evans (EvansCR9@cardiff.ac.uk). This must be sent along with confirmation that your research project has ended and sent within the three months of the research project completion.

Documents reviewed by Committee
The documents reviewed by the Committee were:

Document	Version	Date
Application	V1	-
Research Protocol	V1	16/06/2022
Recruitment Advert	V1	16/06/2022
Participant Information Sheet and Questionnaire	V1	17/06/2022
RI Training Certificates	-	-

Complaints/Appeals

If you are dissatisfied with the decision made by the Committee, please contact the Chair of the Committee via the Committee Secretary (EvansCR9@cardiff.ac.uk) in the first instance to discuss your complaint. If this discussion does not resolve the issue, you are entitled to refer the matter to the Head of School for further consideration. The Head of School may refer the matter to the University Research Integrity and Ethics Committee (URIEC), where this is appropriate. Please be advised that URIEC will not normally interfere with a decision of the Committee and is concerned only with the general principles of natural justice, reasonableness and fairness of the decision.

Please use the Committee reference number on all future correspondence.

The Committee reminds you that it is your responsibility to conduct your research project to the highest ethical standards and to keep all ethical issues arising from your research project under regular review.

You are expected to comply with Cardiff University's policies, procedures and guidance at all times, including, but not limited to, its Policy on the Ethical Conduct of Research involving Human Participants, Human Material or Human Data and our Research Integrity and Governance Code of Practice.

Yours sincerely,

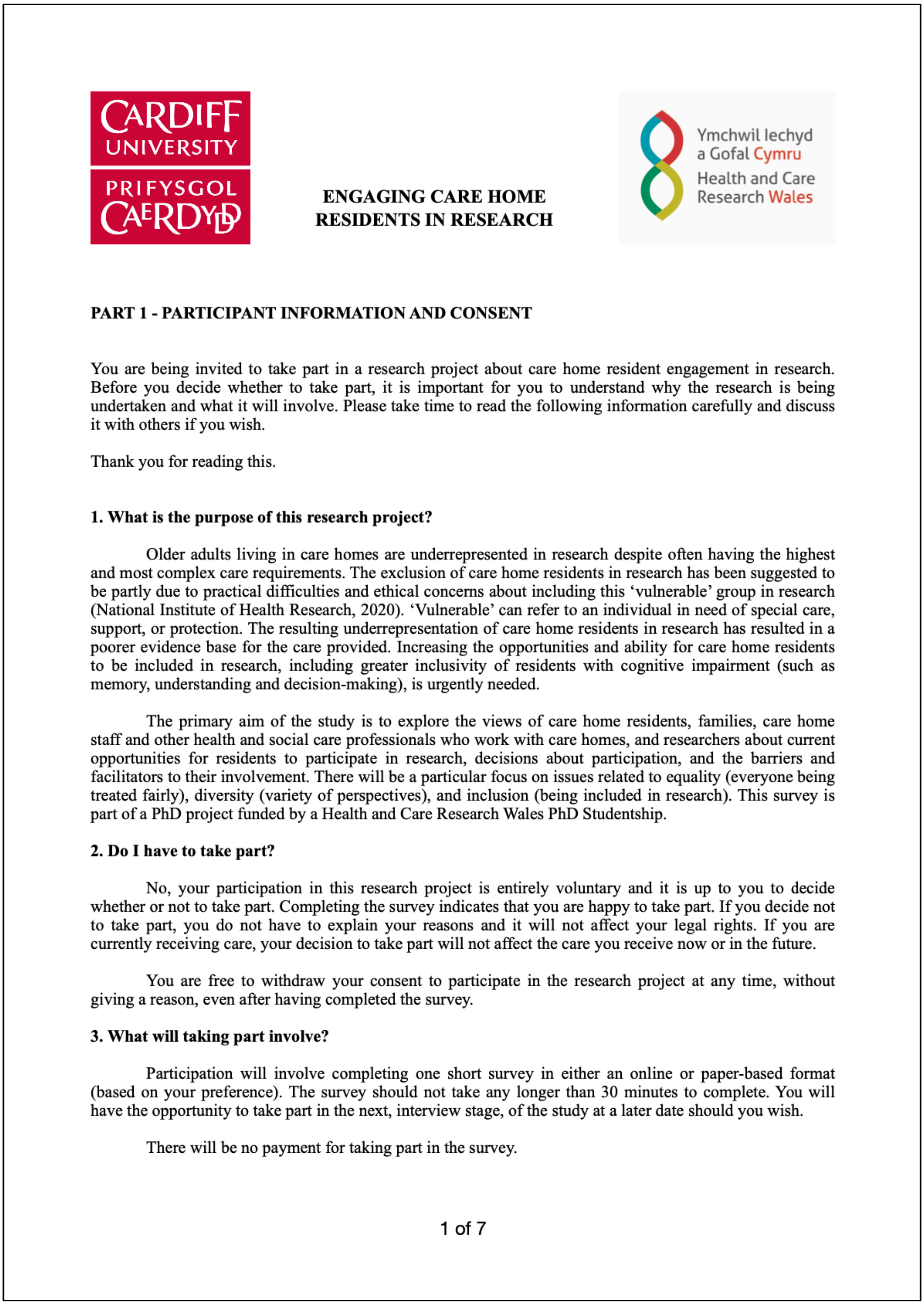
[redacted]

Chair, School of Medicine Research Ethics Committee

Cc Professor Fiona Wood, Dr Victoria Shepherd, Professor Kerry Hood

Registered Charity No. 1136855
Elusen Gofrestredig Rhif. 1136855

Appendix 3.3 Survey study participant information sheet



ENGAGING CARE HOME RESIDENTS IN RESEARCH

PART 1 - PARTICIPANT INFORMATION AND CONSENT

You are being invited to take part in a research project about care home resident engagement in research. Before you decide whether to take part, it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

Thank you for reading this.

1. What is the purpose of this research project?

Older adults living in care homes are underrepresented in research despite often having the highest and most complex care requirements. The exclusion of care home residents in research has been suggested to be partly due to practical difficulties and ethical concerns about including this ‘vulnerable’ group in research (National Institute of Health Research, 2020). ‘Vulnerable’ can refer to an individual in need of special care, support, or protection. The resulting underrepresentation of care home residents in research has resulted in a poorer evidence base for the care provided. Increasing the opportunities and ability for care home residents to be included in research, including greater inclusivity of residents with cognitive impairment (such as memory, understanding and decision-making), is urgently needed.

The primary aim of the study is to explore the views of care home residents, families, care home staff and other health and social care professionals who work with care homes, and researchers about current opportunities for residents to participate in research, decisions about participation, and the barriers and facilitators to their involvement. There will be a particular focus on issues related to equality (everyone being treated fairly), diversity (variety of perspectives), and inclusion (being included in research). This survey is part of a PhD project funded by a Health and Care Research Wales PhD Studentship.

2. Do I have to take part?

No, your participation in this research project is entirely voluntary and it is up to you to decide whether or not to take part. Completing the survey indicates that you are happy to take part. If you decide not to take part, you do not have to explain your reasons and it will not affect your legal rights. If you are currently receiving care, your decision to take part will not affect the care you receive now or in the future.

You are free to withdraw your consent to participate in the research project at any time, without giving a reason, even after having completed the survey.

3. What will taking part involve?

Participation will involve completing one short survey in either an online or paper-based format (based on your preference). The survey should not take any longer than 30 minutes to complete. You will have the opportunity to take part in the next, interview stage, of the study at a later date should you wish.

There will be no payment for taking part in the survey.

4. What are the possible benefits of taking part?

There will be no direct advantages or benefits to you from taking part. However, your contribution will help us understand the views of care home residents, families, care home staff and other health and social care professionals who work with care homes, and researchers about current opportunities for care home residents to participate in research. Your contribution will also help us understand care home residents' decisions about participation and the barriers and facilitators to their involvement. There is only so much information we can get from the research literature and so your views and perspectives are invaluable to our research. We hope that your contribution will help us to develop a communication intervention to support the inclusion of care home residents in decision making and research.

5. What are the possible risks of taking part?

The survey will not include sensitive topics. However, there is a small risk that you may become upset or agitated while completing the survey. If this were to happen, you will be reassured by the researcher, reminded of the purpose of the survey, and be allowed time to pause the survey, and re-assess if you wish to continue. There will be no pressure to continue should you wish to stop. You are also welcome to have someone to help/support you when completing the survey.

6. Will my taking part in this research project be kept confidential?

All information collected from (or about) you during the research project will be kept confidential and any personal information you provide will be managed in accordance with data protection legislation. Please see 'What will happen to my Personal Data?' (below) for further information.

7. What will happen to my Personal Data?

All data collected will be anonymised with the use of a research project number. No identifiable or personal information will be required to take part in this survey.

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. Further information about Data Protection, including:

- your rights
- the legal basis under which Cardiff University processes your personal data for research
- Cardiff University's Data Protection Policy
- how to contact the Cardiff University Data Protection Officer
- how to contact the Information Commissioner's Office

may be found at https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection

Anonymised information will be kept in line with Cardiff University's Research Governance Framework Regulations for non-clinical research for no less than end of project + 5 years or at least 2 years post publication. Your anonymised information may be published in support of the research project and/or retained indefinitely, where it is likely to have continuing value for research purposes.

It will not be possible to withdraw any anonymised data that has already been published.

If you are willing to be contacted in relation to taking part in the next stage of the project, we will securely store the personal data you provide including your name, address, and your email address.

8. What will happen to the results of the research project?

We hope to publish the results of this research project in a PhD thesis, academic journals, and present findings at conferences. Participants will not be identified in any report, publication, or presentation. There is an intention to use direct quotes from participants in the results write up of this study, but no names will be included and there will be no other possibility of recognition.

9. What if there is a problem?

If you wish to complain or have grounds for concerns about any aspect of the manner in which you have been approached or treated during the course of this research, please contact Professor Fiona Wood (Wood@cardiff.ac.uk), the lead supervisor. If your complaint is not managed to your satisfaction, please contact the Chair of the School of Medicine Research Ethics Committee (Claire Evans (EvansCR9@cardiff.ac.uk).

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, you may have grounds for legal action, but you may have to pay for it.

10. Who is organising and funding this research project?

The research is organised by Brittany Nocivelli, Professor Fiona Wood, Dr Victoria Shepherd, Professor Kerry Hood, and Professor Carolyn Wallace at the School of Medicine in Cardiff University. The researchers have a special interest in the inclusion of underrepresented populations in research and developing tools to support the inclusion of populations who are often excluded from research. The research is currently funded by a Health and Care Research Wales PhD Studentship awarded to Brittany Nocivelli.

11. Who has reviewed this research project?

This research project has been reviewed and given a favourable opinion by the Cardiff University School of Medicine Research Ethics Committee.

12. Further information and contact details

Should you have any questions relating to this research project, you may contact us during normal working hours:

Brittany Nocivelli
nocivellibe@cardiff.ac.uk
02920 687185

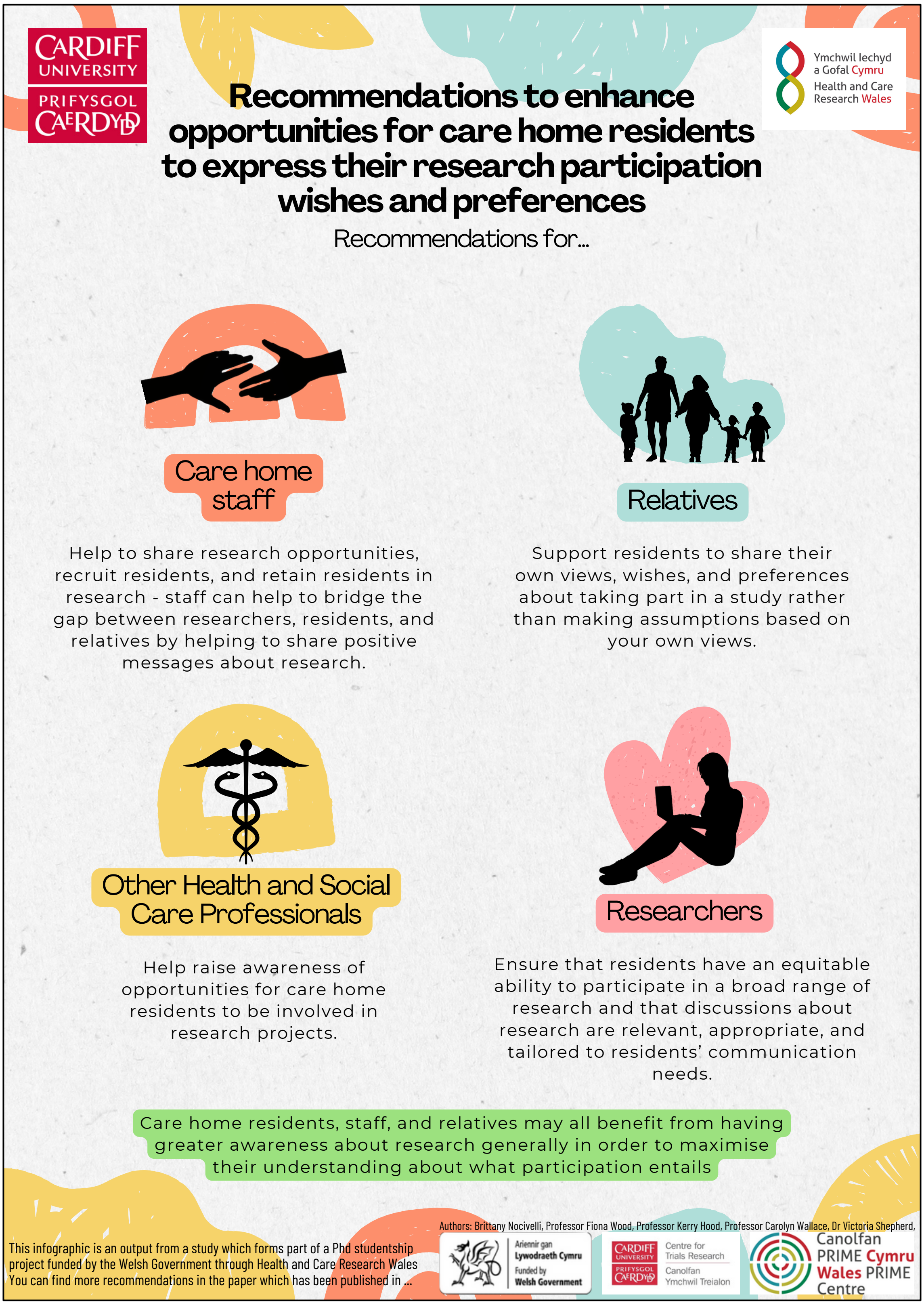
Thank you for considering taking part in this research project. If you decide to participate, you will be given a copy of the Participant Information Sheet to keep for your records.

By completing this survey, I am consenting to take part in this study.

My data will be held securely, and I have a right to withdraw from this study at any time. When my information is no longer required for the purpose of this study, official university procedure will be followed to delete my data.

☐ I understand

Appendix 4.1 Infographic of recommendations for stakeholders to enhance opportunities for care home residents to express their research participation wishes and preferences



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Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

Recommendations to enhance opportunities for care home residents to express their research participation wishes and preferences

Recommendations for...

Care home staff

Help to share research opportunities, recruit residents, and retain residents in research - staff can help to bridge the gap between researchers, residents, and relatives by helping to share positive messages about research.

Relatives

Support residents to share their own views, wishes, and preferences about taking part in a study rather than making assumptions based on your own views.

Other Health and Social Care Professionals

Help raise awareness of opportunities for care home residents to be involved in research projects.

Researchers

Ensure that residents have an equitable ability to participate in a broad range of research and that discussions about research are relevant, appropriate, and tailored to residents' communication needs.

Care home residents, staff, and relatives may all benefit from having greater awareness about research generally in order to maximise their understanding about what participation entails

Authors: Brittany Nocivelli, Professor Fiona Wood, Professor Kerry Hood, Professor Carolyn Wallace, Dr Victoria Shepherd,

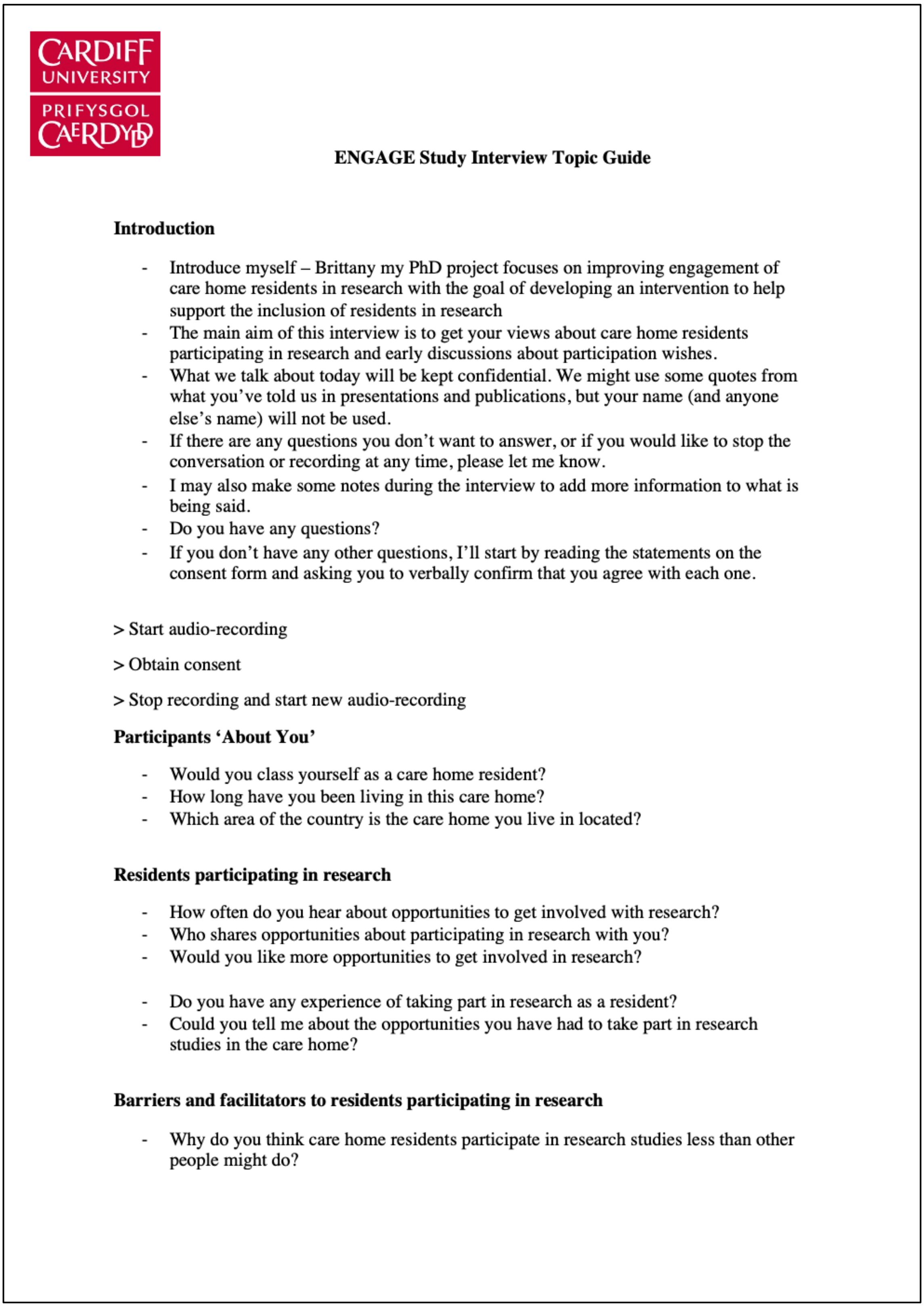
This infographic is an output from a study which forms part of a Phd studentship project funded by the Welsh Government through Health and Care Research Wales
You can find more recommendations in the paper which has been published in ...

Ariennir gan Lywodraeth Cymru
Funded by Welsh Government

CARDIFF UNIVERSITY PRIFYSGOL CAERDYDD
Centre for Trials Research
Canolfan Ymchwil Treialon

Canolfan PRIME Cymru
Wales PRIME Centre

Appendix 4.2 Interview guide



CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

ENGAGE Study Interview Topic Guide

Introduction

- Introduce myself – Brittany my PhD project focuses on improving engagement of care home residents in research with the goal of developing an intervention to help support the inclusion of residents in research
- The main aim of this interview is to get your views about care home residents participating in research and early discussions about participation wishes.
- What we talk about today will be kept confidential. We might use some quotes from what you've told us in presentations and publications, but your name (and anyone else's name) will not be used.
- If there are any questions you don't want to answer, or if you would like to stop the conversation or recording at any time, please let me know.
- I may also make some notes during the interview to add more information to what is being said.
- Do you have any questions?
- If you don't have any other questions, I'll start by reading the statements on the consent form and asking you to verbally confirm that you agree with each one.

> Start audio-recording

> Obtain consent

> Stop recording and start new audio-recording

Participants 'About You'

- Would you class yourself as a care home resident?
- How long have you been living in this care home?
- Which area of the country is the care home you live in located?

Residents participating in research

- How often do you hear about opportunities to get involved with research?
- Who shares opportunities about participating in research with you?
- Would you like more opportunities to get involved in research?

- Do you have any experience of taking part in research as a resident?
- Could you tell me about the opportunities you have had to take part in research studies in the care home?

Barriers and facilitators to residents participating in research

- Why do you think care home residents participate in research studies less than other people might do?

Prompt

- Do you think anything prevents opportunities from reaching residents?
- What do you think would increase research participation from care home residents?

Early discussions about residents wishes and preferences for future research participation/advance planning for research

- Some people have suggested that it might be a good idea to have early discussions with residents about their wishes and preferences for their own research participation. What do you think about that?
- When do you think would be the best time to have these conversations?
- Who should the resident be having these discussions with?
- Do you think that residents would be happy to answer questions about their future preferences should they lose capacity?

Prompts

- For example, should you/a resident lose capacity to consent to taking part in research in the future, then do you think their previous wishes about participating should be considered?

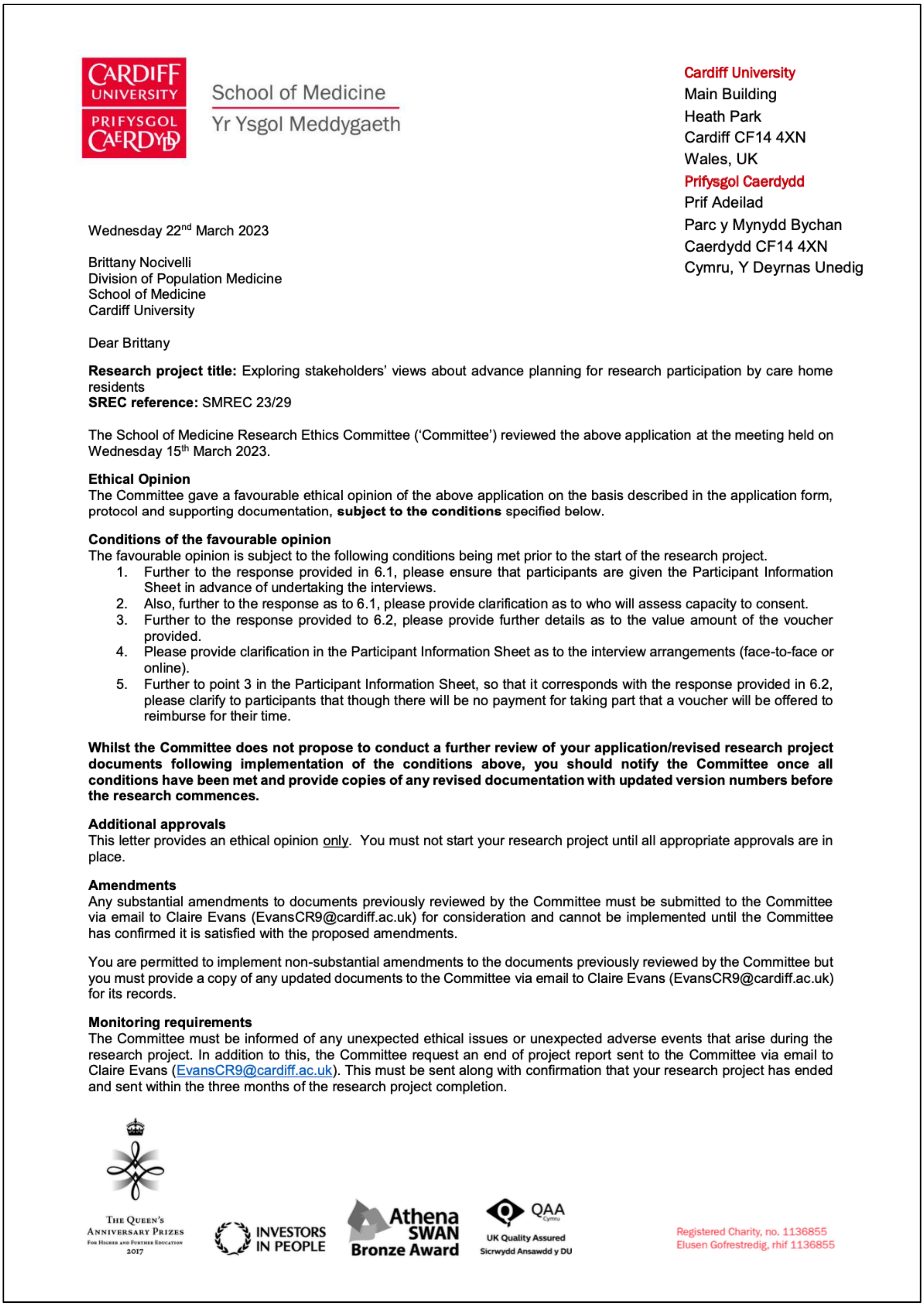
Have you had conversations about future care? Could research preferences fit into this?

If you could be approached or asked about whether you would like to take part in research in the future – how could it be done, when, by who?

End of Interview

- All of the questions I wanted to ask have been covered – before we finish is there anything I haven't covered that you would like to discuss?
- Thank you for taking the time to speak with me and share your views

Appendix 4.3 Interview study Research Ethics Committee approval letter



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Prif Adeilad
Parc y Mynydd Bychan
Caerdydd CF14 4XN
Cymru, Y Deyrnas Unedig

Wednesday 22nd March 2023

Brittany Nocivelli
Division of Population Medicine
School of Medicine
Cardiff University

Dear Brittany

Research project title: Exploring stakeholders' views about advance planning for research participation by care home residents
SREC reference: SMREC 23/29

The School of Medicine Research Ethics Committee ('Committee') reviewed the above application at the meeting held on Wednesday 15th March 2023.

Ethical Opinion
The Committee gave a favourable ethical opinion of the above application on the basis described in the application form, protocol and supporting documentation, **subject to the conditions** specified below.

Conditions of the favourable opinion
The favourable opinion is subject to the following conditions being met prior to the start of the research project.

1. Further to the response provided in 6.1, please ensure that participants are given the Participant Information Sheet in advance of undertaking the interviews.
2. Also, further to the response as to 6.1, please provide clarification as to who will assess capacity to consent.
3. Further to the response provided to 6.2, please provide further details as to the value amount of the voucher provided.
4. Please provide clarification in the Participant Information Sheet as to the interview arrangements (face-to-face or online).
5. Further to point 3 in the Participant Information Sheet, so that it corresponds with the response provided in 6.2, please clarify to participants that though there will be no payment for taking part that a voucher will be offered to reimburse for their time.

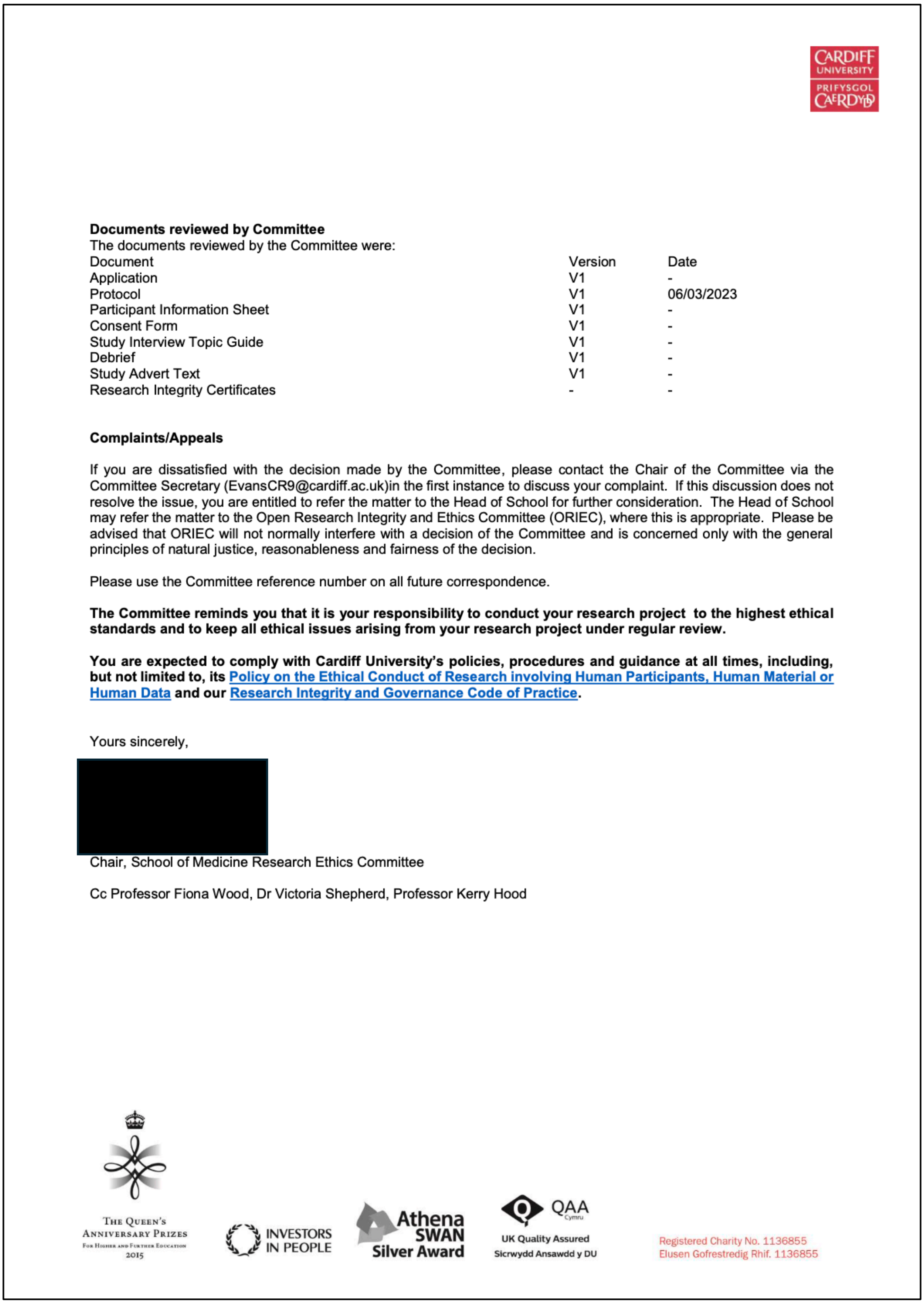
Whilst the Committee does not propose to conduct a further review of your application/revised research project documents following implementation of the conditions above, you should notify the Committee once all conditions have been met and provide copies of any revised documentation with updated version numbers before the research commences.

Additional approvals
This letter provides an ethical opinion only. You must not start your research project until all appropriate approvals are in place.

Amendments
Any substantial amendments to documents previously reviewed by the Committee must be submitted to the Committee via email to Claire Evans (EvansCR9@cardiff.ac.uk) for consideration and cannot be implemented until the Committee has confirmed it is satisfied with the proposed amendments.

You are permitted to implement non-substantial amendments to the documents previously reviewed by the Committee but you must provide a copy of any updated documents to the Committee via email to Claire Evans (EvansCR9@cardiff.ac.uk) for its records.

Monitoring requirements
The Committee must be informed of any unexpected ethical issues or unexpected adverse events that arise during the research project. In addition to this, the Committee request an end of project report sent to the Committee via email to Claire Evans (EvansCR9@cardiff.ac.uk). This must be sent along with confirmation that your research project has ended and sent within the three months of the research project completion.



Documents reviewed by Committee

The documents reviewed by the Committee were:

Document	Version	Date
Application	V1	-
Protocol	V1	06/03/2023
Participant Information Sheet	V1	-
Consent Form	V1	-
Study Interview Topic Guide	V1	-
Debrief	V1	-
Study Advert Text	V1	-
Research Integrity Certificates	-	-

Complaints/Appeals

If you are dissatisfied with the decision made by the Committee, please contact the Chair of the Committee via the Committee Secretary (EvansCR9@cardiff.ac.uk)in the first instance to discuss your complaint. If this discussion does not resolve the issue, you are entitled to refer the matter to the Head of School for further consideration. The Head of School may refer the matter to the Open Research Integrity and Ethics Committee (ORIEC), where this is appropriate. Please be advised that ORIEC will not normally interfere with a decision of the Committee and is concerned only with the general principles of natural justice, reasonableness and fairness of the decision.

Please use the Committee reference number on all future correspondence.

The Committee reminds you that it is your responsibility to conduct your research project to the highest ethical standards and to keep all ethical issues arising from your research project under regular review.

You are expected to comply with Cardiff University's policies, procedures and guidance at all times, including, but not limited to, its Policy on the Ethical Conduct of Research involving Human Participants, Human Material or Human Data and our Research Integrity and Governance Code of Practice.

Yours sincerely,

[redacted]

Chair, School of Medicine Research Ethics Committee

Cc Professor Fiona Wood, Dr Victoria Shepherd, Professor Kerry Hood

Registered Charity No. 1136855
Elusen Gofrestredig Rhif. 1136855

Appendix 4.4 Interview study participant information sheet

PARTICIPANT INFORMATION SHEET

Exploring stakeholders' views about advance planning for research participation by care home residents

You are being invited to take part in a research project. Before you decide whether to take part, it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

Thank you for reading this.

1. What is the purpose of this research project?

Older people living in care homes are less likely to have the opportunity to take part in research than other groups of people. This means that we know less about how best to care for people living in care homes. Increasing the opportunities for care home residents to take part in research, including residents who have dementia, is much needed.

The aim of this study is to explore the views of care home residents, families, staff, researchers, and other professionals who work with care homes, about the opportunities for residents to take part in research. We would like to know their views about whether encouraging residents to discuss their wishes and preferences about research might help, and when is the best time for these discussions to take place.

This survey is part of a PhD project funded by the Welsh Government through a Health and Care Research Wales PhD Studentship.

2. Do I have to take part?

No, your participation in this research project is entirely voluntary and it is up to you to decide whether or not to take part. If you decide to take part, we will ask you to tick a consent box. If you decide not to take part, you do not have to explain your reasons and it will not affect your legal rights. If you are currently receiving care, your decision to take part will not affect the care you receive.

You are free to withdraw your consent to participate in the research project at any time, without giving a reason.

3. What will taking part involve?

Participation will involve taking part in one semi-structured interview, either online or face-to-face. The interview may take up to an hour to complete.

There will be no payment for taking part in the interview, instead a £15 Amazon voucher, or gift equivalent for residents at the participants' request, will be given in recognition of your time.

4. What are the possible benefits of taking part?

There will be no direct advantages or benefits to you from taking part, but your contribution will help us understand your views about care home residents participating in research. We hope that your contribution will also help us to develop a communication tool to support the inclusion of care home residents in decision making and research.

5. What are the possible risks of taking part?

The interview questions may include sensitive topics. There is a small risk that participants may become upset or agitated while completing the interview. If this were to happen, we will aim to reassure you, remind you about the purpose of the interview, allow time to pause the interview, and check if you wish to continue.

6. Will my taking part in this research project be kept confidential?

All information collected from (or about) you during the research project will be kept confidential and any personal information you provide will be managed in accordance with data protection legislation. Please see ‘What will happen to my Personal Data?’ (below) for further information.

7. What will happen to my Personal Data?

All data collected will be anonymised with the use of a research project number. No identifiable or personal information will be required to take part in this interview.

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. Further information about Data Protection, including:

- your rights
- the legal basis under which Cardiff University processes your personal data for research
- Cardiff University’s Data Protection Policy
- how to contact the Cardiff University Data Protection Officer
- how to contact the Information Commissioner’s Office

may be found at https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection

Anonymised information will be kept in line with Cardiff University’s Research Governance Framework Regulations for non-clinical research for no less than end of project + 5 years or at least 2 years post publication. Your anonymised information may be published in support of the research project and/or retained indefinitely, where it is likely to have continuing value for research purposes.

8. What will happen to the results of the research project?

We hope to publish the results of this research project in a PhD thesis, academic journals, and present at conferences. You will not be identified in any report, publication, or presentation. We may use direct quotes from you in the write up of this study, but no names will be included and there will be no other possibility of recognition.

9. What if there is a problem?

If you wish to complain or have grounds for concerns about any aspect of the manner in which you have been approached or treated during the course of this research, please contact Fiona Wood (wood@cardiff.ac.uk). If your complaint is not managed to your satisfaction, please contact the School of Medicine Research Ethics Committee (EvansCR9@cardiff.ac.uk).

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, you may have grounds for legal action, but you may have to pay for it.

10. Who is organising and funding this research project?

The research is organised by Brittany Nocivelli, Professor Fiona Wood, Dr Victoria Shepherd, and Professor Kerry Hood at the School of Medicine in Cardiff University, and Professor Carolyn Wallace at the University of South Wales. The researchers have a special interest in the inclusion of underrepresented populations in research and developing tools to support the inclusion of populations who are often excluded from research. The research is currently funded by a Health and Care Research Wales PhD Studentship awarded to Brittany Nocivelli.

11. Who has reviewed this research project?

This research project has been reviewed and given a favourable opinion by the Cardiff University School of Medicine Research Ethics Committee.

12. Further information and contact details

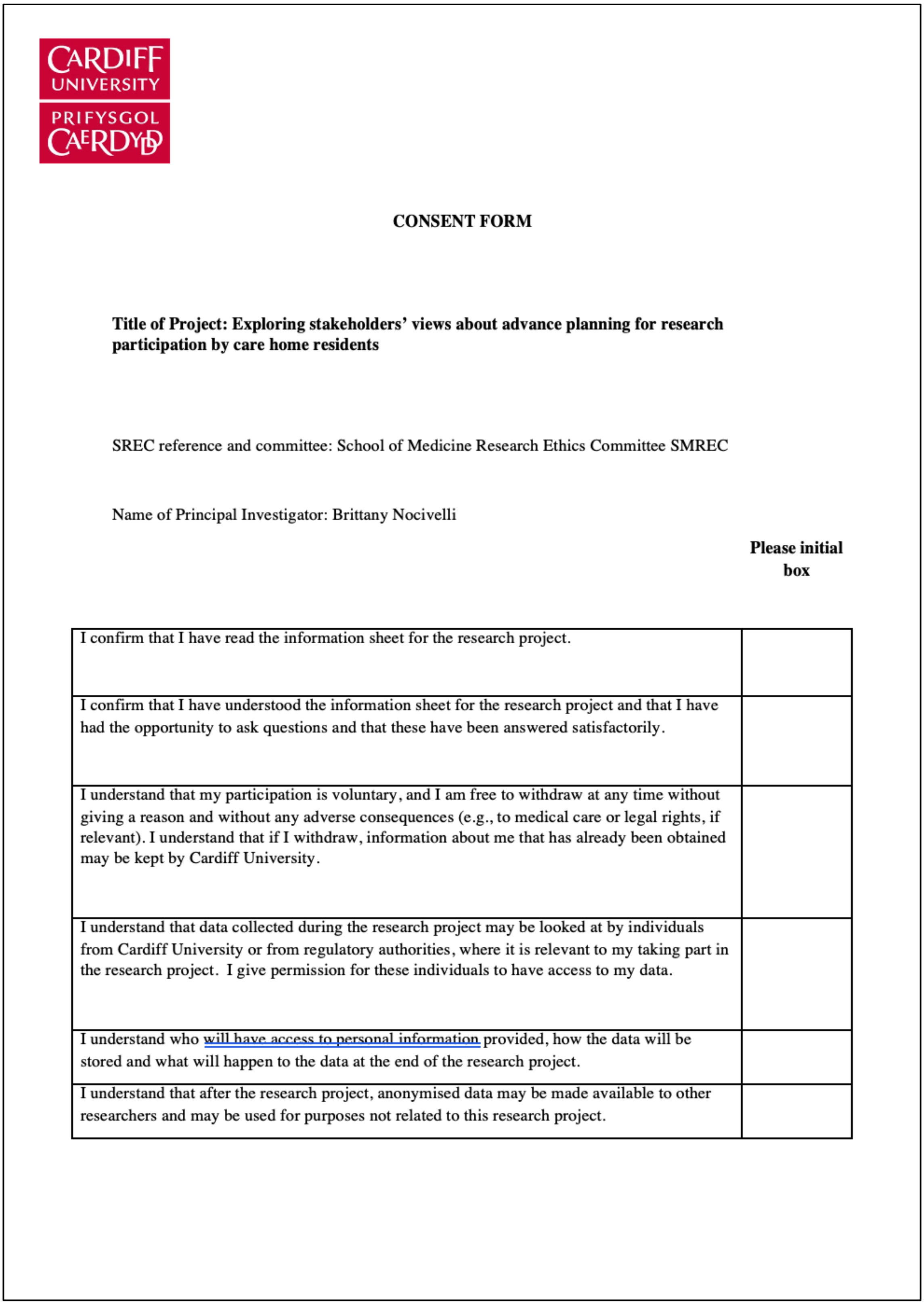
Should you have any questions relating to this research project, you may contact us during normal working hours:

Brittany Nocivelli

nocivellibe@cardiff.ac.uk

02920687185

Appendix 4.5 Interview study consent form



CARDIFF
UNIVERSITY
PRIFYSGOL
CAERDYDD

CONSENT FORM

Title of Project: Exploring stakeholders’ views about advance planning for research participation by care home residents

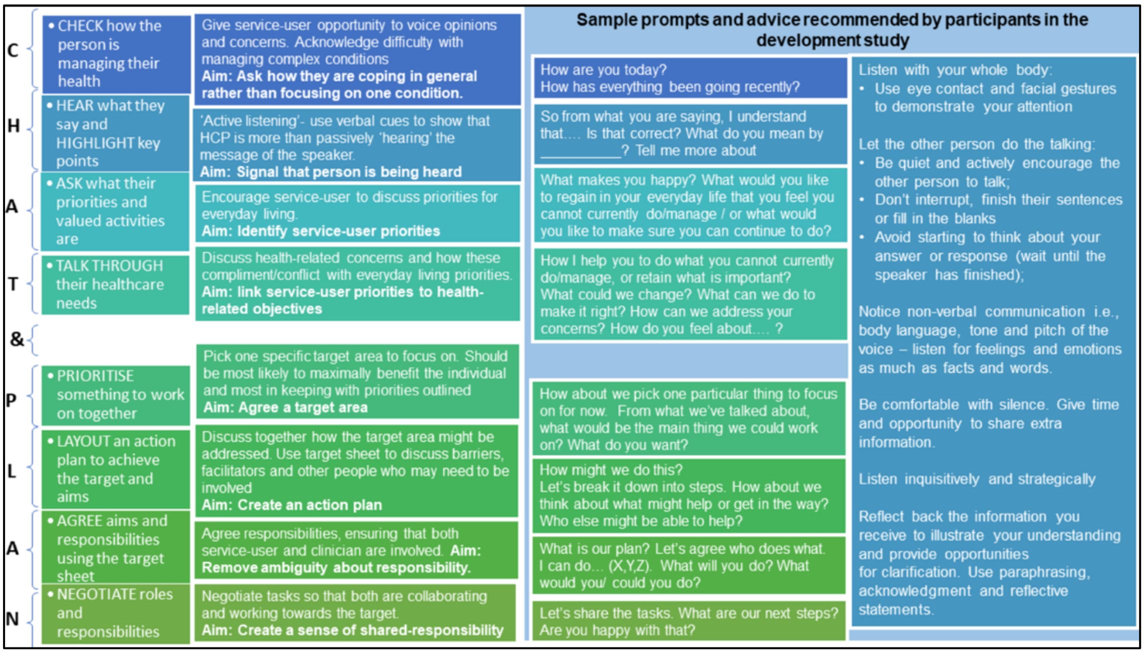
SREC reference and committee: School of Medicine Research Ethics Committee SMREC

Name of Principal Investigator: Brittany Nocivelli

	Please initial box
I confirm that I have read the information sheet for the research project.	
I confirm that I have understood the information sheet for the research project and that I have had the opportunity to ask questions and that these have been answered satisfactorily.	
I understand that my participation is voluntary, and I am free to withdraw at any time without giving a reason and without any adverse consequences (e.g., to medical care or legal rights, if relevant). I understand that if I withdraw, information about me that has already been obtained may be kept by Cardiff University.	
I understand that data collected during the research project may be looked at by individuals from Cardiff University or from regulatory authorities, where it is relevant to my taking part in the research project. I give permission for these individuals to have access to my data.	
I understand who will have access to personal information provided, how the data will be stored and what will happen to the data at the end of the research project.	
I understand that after the research project, anonymised data may be made available to other researchers and may be used for purposes not related to this research project.	

I understand that it will not be possible to identify me from this data that is seen and used by other researchers, for ethically approved research projects, on the understanding that confidentiality will be maintained.	
I consent to being audio recorded for the purposes of the research project and I understand how it will be used in the research.	
I understand that anonymised excerpts and/or verbatim quotes from my interview may be used as part of the research publication.	
I understand how the findings and results of the research project will be written up and published.	
I agree to take part in this research project.	

Appendix 5.1 CHAT&PLAN intervention



			Sample prompts and advice recommended by participants in the development study
C	• CHECK how the person is managing their health	Give service-user opportunity to voice opinions and concerns. Acknowledge difficulty with managing complex conditions **Aim: Ask how they are coping in general rather than focusing on one condition.**	How are you today? How has everything been going recently?
H	• HEAR what they say and HIGHLIGHT key points	'Active listening'- use verbal cues to show that HCP is more than passively 'hearing' the message of the speaker. **Aim: Signal that person is being heard**	So from what you are saying, I understand that…. Is that correct? What do you mean by __________? Tell me more about
A	• ASK what their priorities and valued activities are	Encourage service-user to discuss priorities for everyday living. **Aim: Identify service-user priorities**	What makes you happy? What would you like to regain in your everyday life that you feel you cannot currently do/manage / or what would you like to make sure you can continue to do?
T	• TALK THROUGH their healthcare needs	Discuss health-related concerns and how these compliment/conflict with everyday living priorities. **Aim: link service-user priorities to health-related objectives**	How I help you to do what you cannot currently do/manage, or retain what is important? What could we change? What can we do to make it right? How can we address your concerns? How do you feel about…. ?
&			
P	• PRIORITISE something to work on together	Pick one specific target area to focus on. Should be most likely to maximally benefit the individual and most in keeping with priorities outlined **Aim: Agree a target area**	How about we pick one particular thing to focus on for now. From what we've talked about, what would be the main thing we could work on? What do you want?
L	• LAYOUT an action plan to achieve the target and aims	Discuss together how the target area might be addressed. Use target sheet to discuss barriers, facilitators and other people who may need to be involved **Aim: Create an action plan**	How might we do this? Let's break it down into steps. How about we think about what might help or get in the way? Who else might be able to help?
A	• AGREE aims and responsibilities using the target sheet	Agree responsibilities, ensuring that both service-user and clinician are involved. **Aim: Remove ambiguity about responsibility.**	What is our plan? Let's agree who does what. I can do… (X,Y,Z). What will you do? What would you/ could you do?
N	• NEGOTIATE roles and responsibilities	Negotiate tasks so that both are collaborating and working towards the target. **Aim: Create a sense of shared-responsibility**	Let's share the tasks. What are our next steps? Are you happy with that?

Listen with your whole body:
- Use eye contact and facial gestures to demonstrate your attention

Let the other person do the talking:
- Be quiet and actively encourage the other person to talk;
- Don't interrupt, finish their sentences or fill in the blanks
- Avoid starting to think about your answer or response (wait until the speaker has finished);

Notice non-verbal communication i.e., body language, tone and pitch of the voice – listen for feelings and emotions as much as facts and words.

Be comfortable with silence. Give time and opportunity to share extra information.

Listen inquisitively and strategically

Reflect back the information you receive to illustrate your understanding and provide opportunities for clarification. Use paraphrasing, acknowledgment and reflective statements.

Appendix 5.2 Caring Conversations intervention framework

Having caring conversations

Be Courageous
What would happen if we gave this a go?

Connect Emotionally
How did this make you feel?

Be Curious
Help me to understand what is happening?

Consider Other Perspectives
What do others think?

Collaborate
How can we work together to make this happen?

Compromise
What is real and possible?

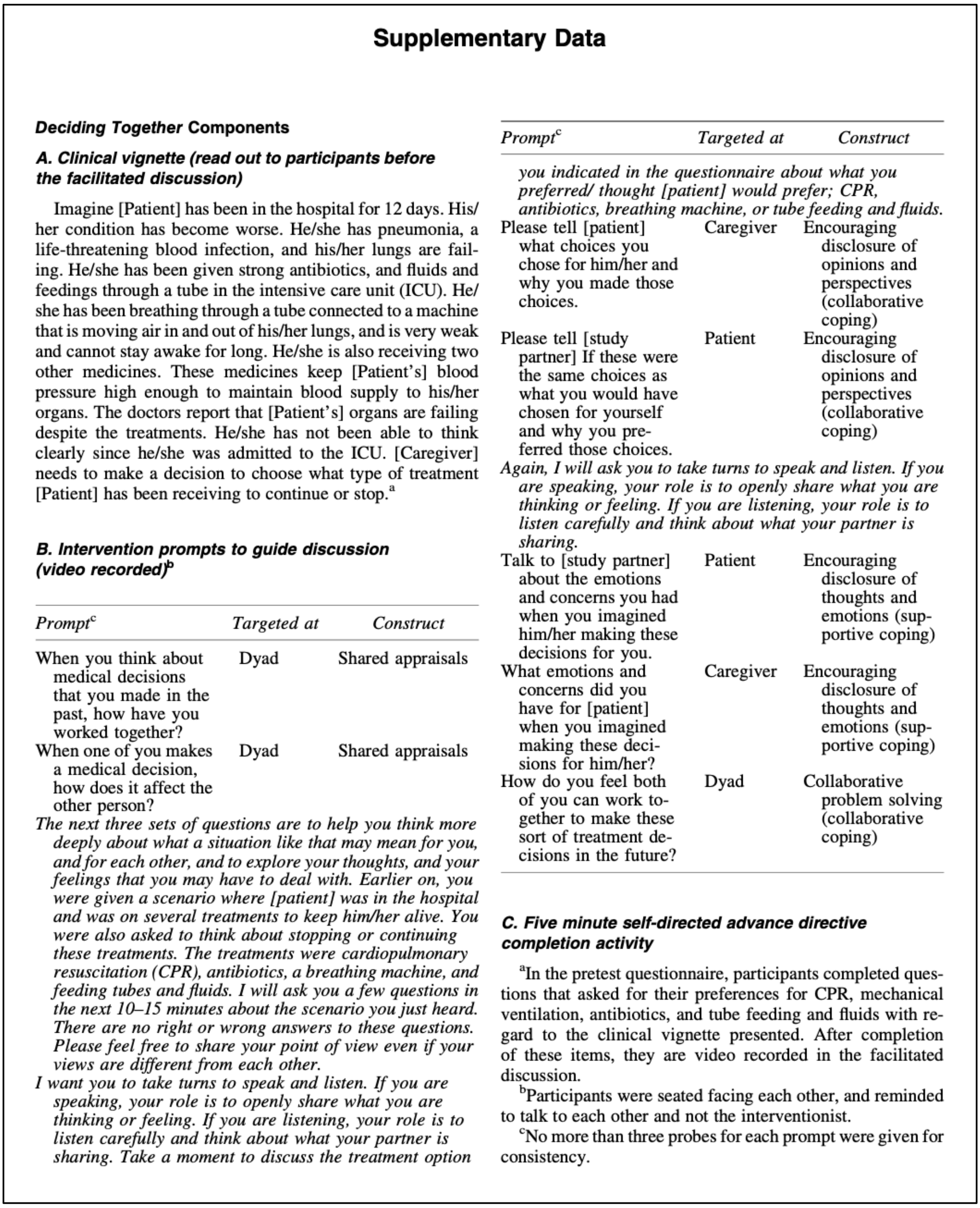
Celebrate
What worked well?

My home life®

www.myhomelife.org.uk

Dewar B and Nolan M (2013) Caring about caring: Developing a model to implement compassionate relationship centred care in an older people care setting, *International Journal of Nursing Studies*, 50(9):1247-58.

Appendix 5.3 Deciding Together intervention



Supplementary Data

Deciding Together Components

A. Clinical vignette (read out to participants before the facilitated discussion)

Imagine [Patient] has been in the hospital for 12 days. His/her condition has become worse. He/she has pneumonia, a life-threatening blood infection, and his/her lungs are failing. He/she has been given strong antibiotics, and fluids and feedings through a tube in the intensive care unit (ICU). He/she has been breathing through a tube connected to a machine that is moving air in and out of his/her lungs, and is very weak and cannot stay awake for long. He/she is also receiving two other medicines. These medicines keep [Patient's] blood pressure high enough to maintain blood supply to his/her organs. The doctors report that [Patient's] organs are failing despite the treatments. He/she has not been able to think clearly since he/she was admitted to the ICU. [Caregiver] needs to make a decision to choose what type of treatment [Patient] has been receiving to continue or stop.[a]

B. Intervention prompts to guide discussion (video recorded)[b]

Prompt[c]	*Targeted at*	*Construct*
When you think about medical decisions that you made in the past, how have you worked together?	Dyad	Shared appraisals
When one of you makes a medical decision, how does it affect the other person?	Dyad	Shared appraisals
The next three sets of questions are to help you think more deeply about what a situation like that may mean for you, and for each other, and to explore your thoughts, and your feelings that you may have to deal with. Earlier on, you were given a scenario where [patient] was in the hospital and was on several treatments to keep him/her alive. You were also asked to think about stopping or continuing these treatments. The treatments were cardiopulmonary resuscitation (CPR), antibiotics, a breathing machine, and feeding tubes and fluids. I will ask you a few questions in the next 10–15 minutes about the scenario you just heard. There are no right or wrong answers to these questions. Please feel free to share your point of view even if your views are different from each other.		
I want you to take turns to speak and listen. If you are speaking, your role is to openly share what you are thinking or feeling. If you are listening, your role is to listen carefully and think about what your partner is sharing. Take a moment to discuss the treatment option you indicated in the questionnaire about what you preferred/ thought [patient] would prefer; CPR, antibiotics, breathing machine, or tube feeding and fluids.		
Please tell [patient] what choices you chose for him/her and why you made those choices.	Caregiver	Encouraging disclosure of opinions and perspectives (collaborative coping)
Please tell [study partner] If these were the same choices as what you would have chosen for yourself and why you preferred those choices.	Patient	Encouraging disclosure of opinions and perspectives (collaborative coping)
Again, I will ask you to take turns to speak and listen. If you are speaking, your role is to openly share what you are thinking or feeling. If you are listening, your role is to listen carefully and think about what your partner is sharing.		
Talk to [study partner] about the emotions and concerns you had when you imagined him/her making these decisions for you.	Patient	Encouraging disclosure of thoughts and emotions (supportive coping)
What emotions and concerns did you have for [patient] when you imagined making these decisions for him/her?	Caregiver	Encouraging disclosure of thoughts and emotions (supportive coping)
How do you feel both of you can work together to make these sort of treatment decisions in the future?	Dyad	Collaborative problem solving (collaborative coping)

C. Five minute self-directed advance directive completion activity

[a] In the pretest questionnaire, participants completed questions that asked for their preferences for CPR, mechanical ventilation, antibiotics, and tube feeding and fluids with regard to the clinical vignette presented. After completion of these items, they are video recorded in the facilitated discussion.

[b] Participants were seated facing each other, and reminded to talk to each other and not the interventionist.

[c] No more than three probes for each prompt were given for consistency.

Appendix 5.4 ACP Medizinisch Begleitet tool resource

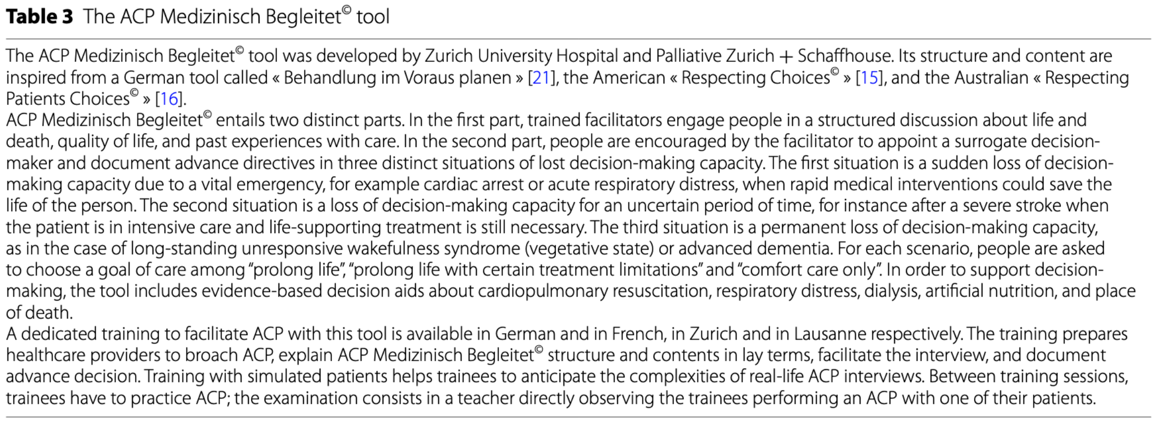


Table 3 The ACP Medizinisch Begleitet© tool

The ACP Medizinisch Begleitet© tool was developed by Zurich University Hospital and Palliative Zurich + Schaffhouse. Its structure and content are inspired from a German tool called « Behandlung im Voraus planen » [21], the American « Respecting Choices© » [15], and the Australian « Respecting Patients Choices© » [16].

ACP Medizinisch Begleitet© entails two distinct parts. In the first part, trained facilitators engage people in a structured discussion about life and death, quality of life, and past experiences with care. In the second part, people are encouraged by the facilitator to appoint a surrogate decision-maker and document advance directives in three distinct situations of lost decision-making capacity. The first situation is a sudden loss of decision-making capacity due to a vital emergency, for example cardiac arrest or acute respiratory distress, when rapid medical interventions could save the life of the person. The second situation is a loss of decision-making capacity for an uncertain period of time, for instance after a severe stroke when the patient is in intensive care and life-supporting treatment is still necessary. The third situation is a permanent loss of decision-making capacity, as in the case of long-standing unresponsive wakefulness syndrome (vegetative state) or advanced dementia. For each scenario, people are asked to choose a goal of care among "prolong life", "prolong life with certain treatment limitations" and "comfort care only". In order to support decision-making, the tool includes evidence-based decision aids about cardiopulmonary resuscitation, respiratory distress, dialysis, artificial nutrition, and place of death.

A dedicated training to facilitate ACP with this tool is available in German and in French, in Zurich and in Lausanne respectively. The training prepares healthcare providers to broach ACP, explain ACP Medizinisch Begleitet© structure and contents in lay terms, facilitate the interview, and document advance decision. Training with simulated patients helps trainees to anticipate the complexities of real-life ACP interviews. Between training sessions, trainees have to practice ACP; the examination consists in a teacher directly observing the trainees performing an ACP with one of their patients.

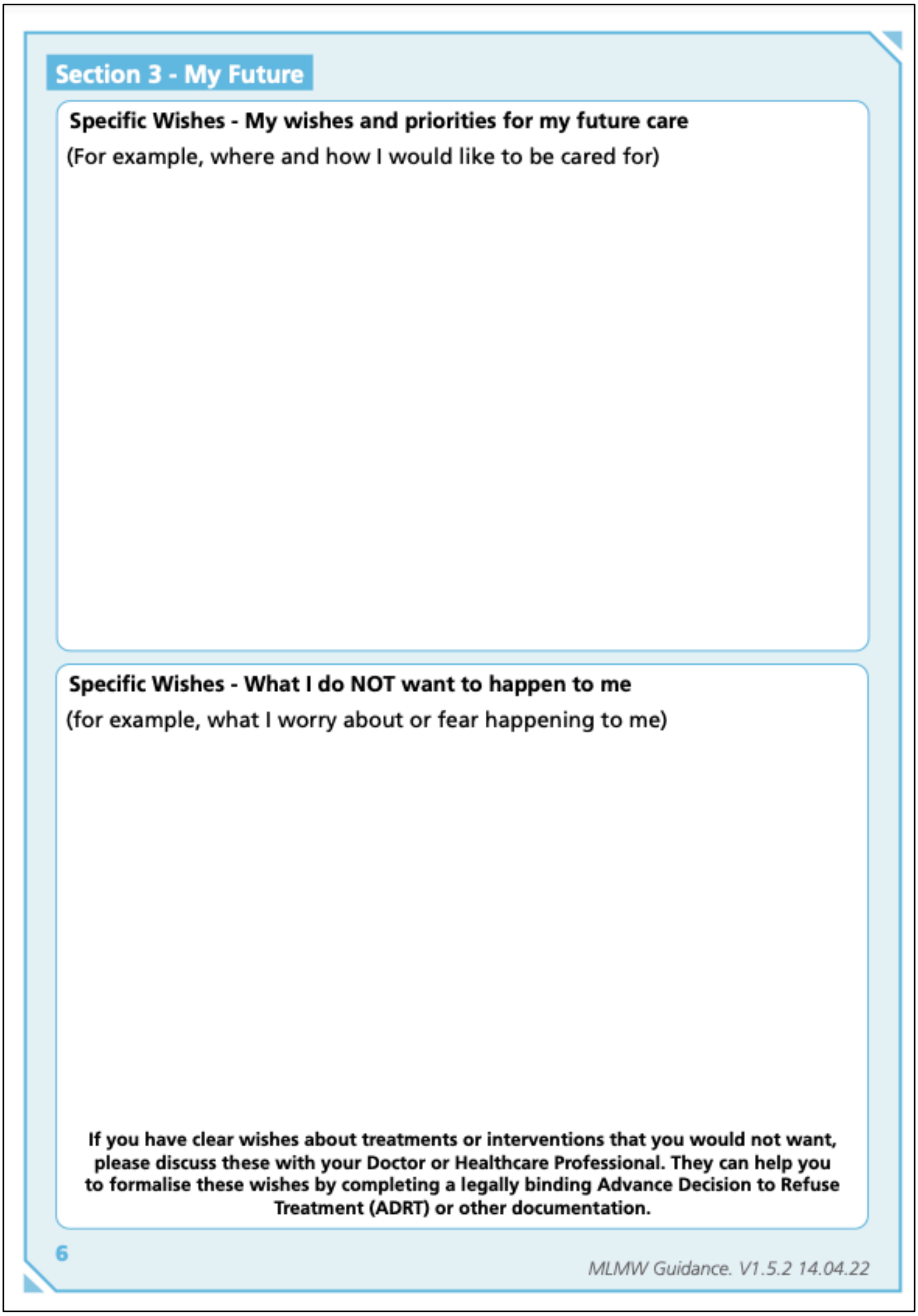
Appendix 5.5 Fink Cards resource

https://finkcards.com/collections/health/products/advance-care-planning?variant=2817933124

Appendix 5.6 Go Wish resource

Appendix 5.7 My Life, My Wishes resource

(Example pages from Advance Care Plan document and guidance booklet, full links below)



Section 3 - My Future

Specific Wishes - My wishes and priorities for my future care

(For example, where and how I would like to be cared for)

Specific Wishes - What I do NOT want to happen to me

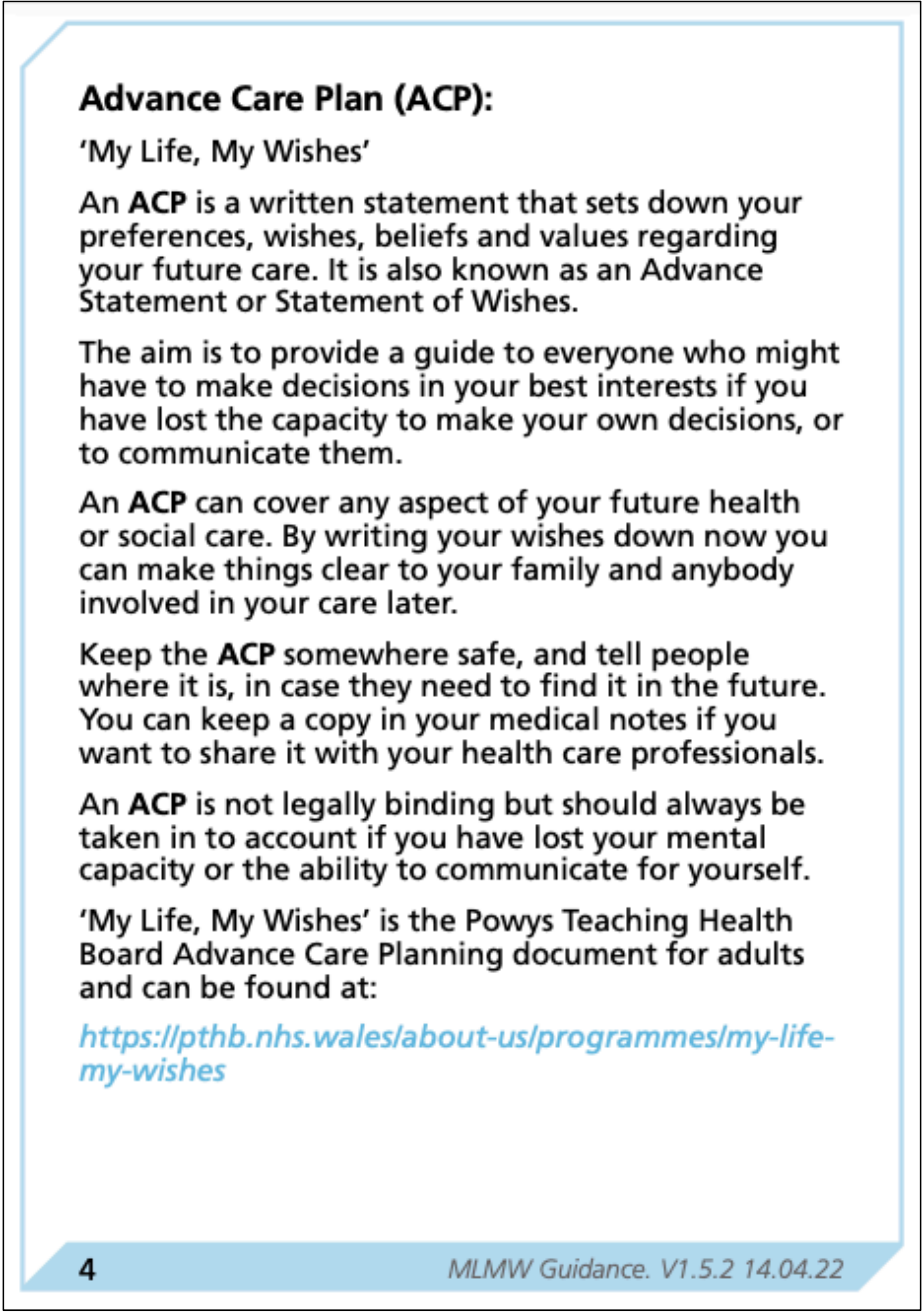
(for example, what I worry about or fear happening to me)

If you have clear wishes about treatments or interventions that you would not want, please discuss these with your Doctor or Healthcare Professional. They can help you to formalise these wishes by completing a legally binding Advance Decision to Refuse Treatment (ADRT) or other documentation.

6

MLMW Guidance. V1.5.2 14.04.22

My Life, My Wishes Advance Care Plan Document: https://pthb.nhs.wales/about-us/programmes/my-life-my-wishes/mlmw-booklet-english/



Advance Care Plan (ACP):

'My Life, My Wishes'

An **ACP** is a written statement that sets down your preferences, wishes, beliefs and values regarding your future care. It is also known as an Advance Statement or Statement of Wishes.

The aim is to provide a guide to everyone who might have to make decisions in your best interests if you have lost the capacity to make your own decisions, or to communicate them.

An **ACP** can cover any aspect of your future health or social care. By writing your wishes down now you can make things clear to your family and anybody involved in your care later.

Keep the **ACP** somewhere safe, and tell people where it is, in case they need to find it in the future. You can keep a copy in your medical notes if you want to share it with your health care professionals.

An **ACP** is not legally binding but should always be taken in to account if you have lost your mental capacity or the ability to communicate for yourself.

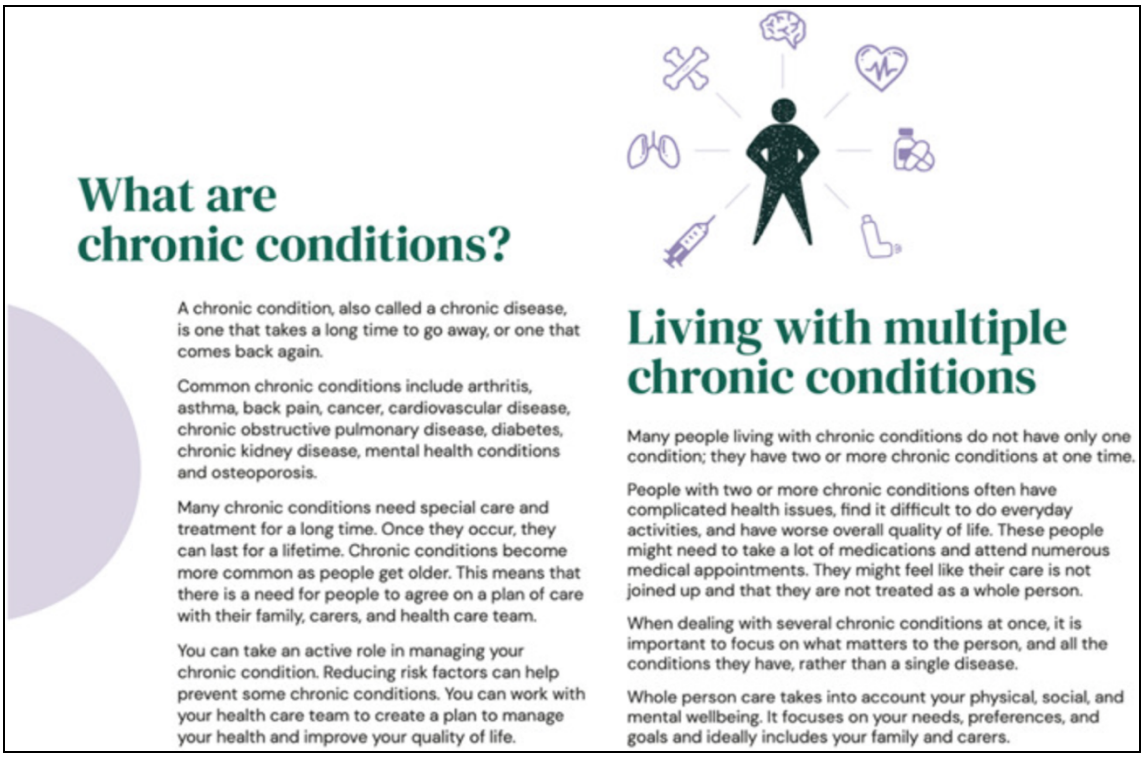
'My Life, My Wishes' is the Powys Teaching Health Board Advance Care Planning document for adults and can be found at:

https://pthb.nhs.wales/about-us/programmes/my-life-my-wishes

4 *MLMW Guidance. V1.5.2 14.04.22*

My Life, My Wishes Information Guidance Booklet: https://pthb.nhs.wales/about-us/programmes/my-life-my-wishes/my-life-my-wishes-guidance-notes-english/

Appendix 5.8 My Wellbeing Journal resource
(Example pages and prompt card with questions, full link below)



What are chronic conditions?

A chronic condition, also called a chronic disease, is one that takes a long time to go away, or one that comes back again.

Common chronic conditions include arthritis, asthma, back pain, cancer, cardiovascular disease, chronic obstructive pulmonary disease, diabetes, chronic kidney disease, mental health conditions and osteoporosis.

Many chronic conditions need special care and treatment for a long time. Once they occur, they can last for a lifetime. Chronic conditions become more common as people get older. This means that there is a need for people to agree on a plan of care with their family, carers, and health care team.

You can take an active role in managing your chronic condition. Reducing risk factors can help prevent some chronic conditions. You can work with your health care team to create a plan to manage your health and improve your quality of life.

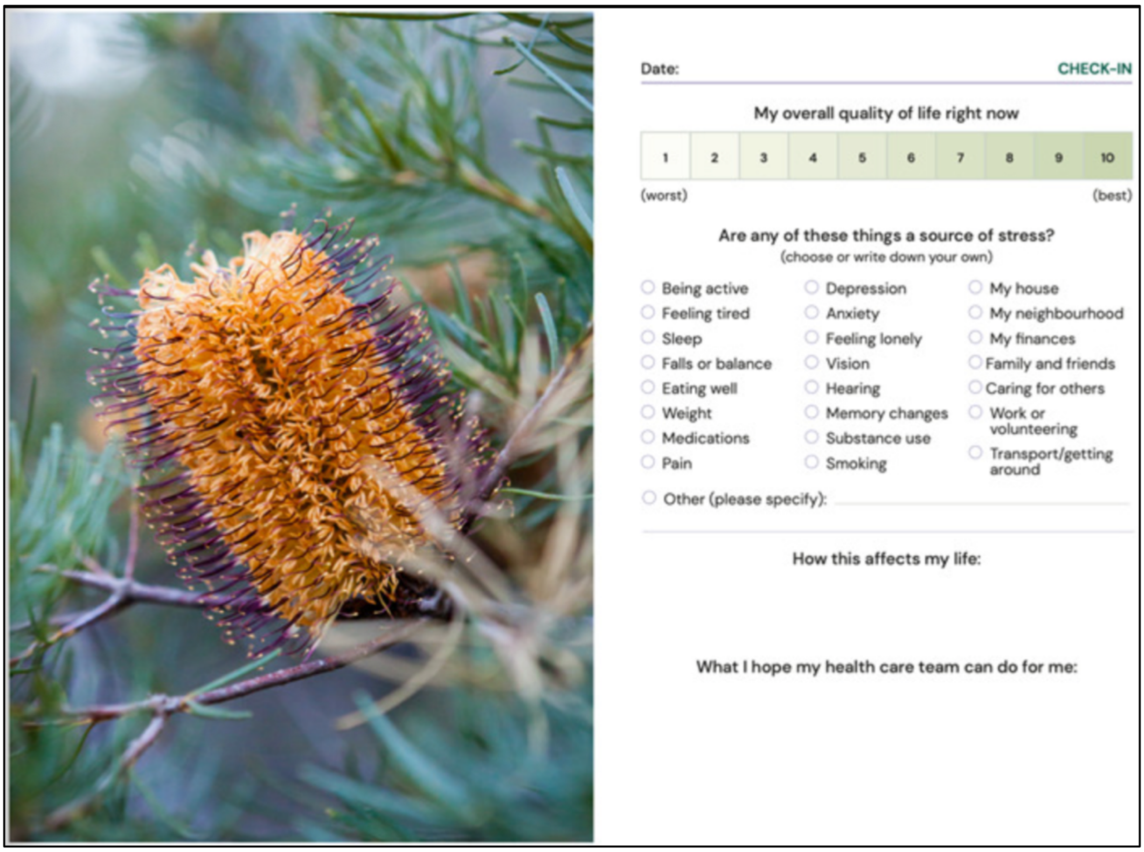
Living with multiple chronic conditions

Many people living with chronic conditions do not have only one condition; they have two or more chronic conditions at one time.

People with two or more chronic conditions often have complicated health issues, find it difficult to do everyday activities, and have worse overall quality of life. These people might need to take a lot of medications and attend numerous medical appointments. They might feel like their care is not joined up and that they are not treated as a whole person.

When dealing with several chronic conditions at once, it is important to focus on what matters to the person, and all the conditions they have, rather than a single disease.

Whole person care takes into account your physical, social, and mental wellbeing. It focuses on your needs, preferences, and goals and ideally includes your family and carers.



Date: **CHECK-IN**

My overall quality of life right now

1	2	3	4	5	6	7	8	9	10

(worst) (best)

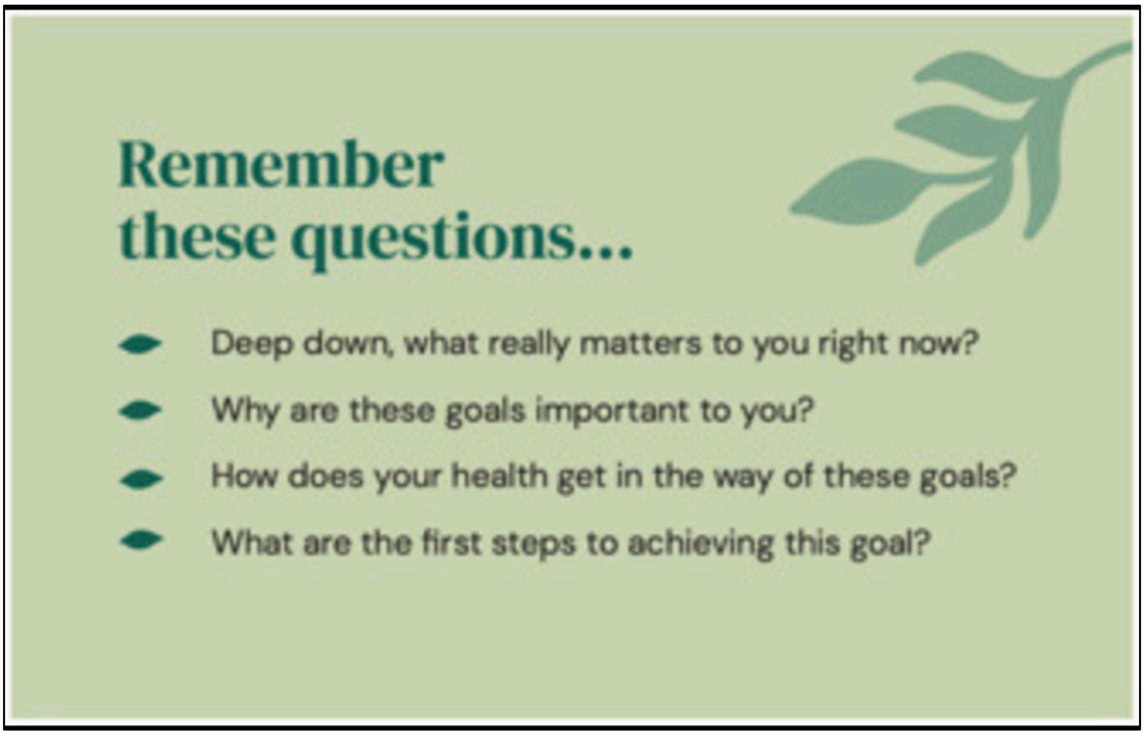
Are any of these things a source of stress?
(choose or write down your own)

○ Being active
○ Feeling tired
○ Sleep
○ Falls or balance
○ Eating well
○ Weight
○ Medications
○ Pain
○ Depression
○ Anxiety
○ Feeling lonely
○ Vision
○ Hearing
○ Memory changes
○ Substance use
○ Smoking
○ My house
○ My neighbourhood
○ My finances
○ Family and friends
○ Caring for others
○ Work or volunteering
○ Transport/getting around

○ Other (please specify):

How this affects my life:

What I hope my health care team can do for me:



Remember these questions...

- Deep down, what really matters to you right now?
- Why are these goals important to you?
- How does your health get in the way of these goals?
- What are the first steps to achieving this goal?

Appendix 5.9 Photo Story Booklet resource

(Example: photo story about bringing someone for support)

Two heads are better

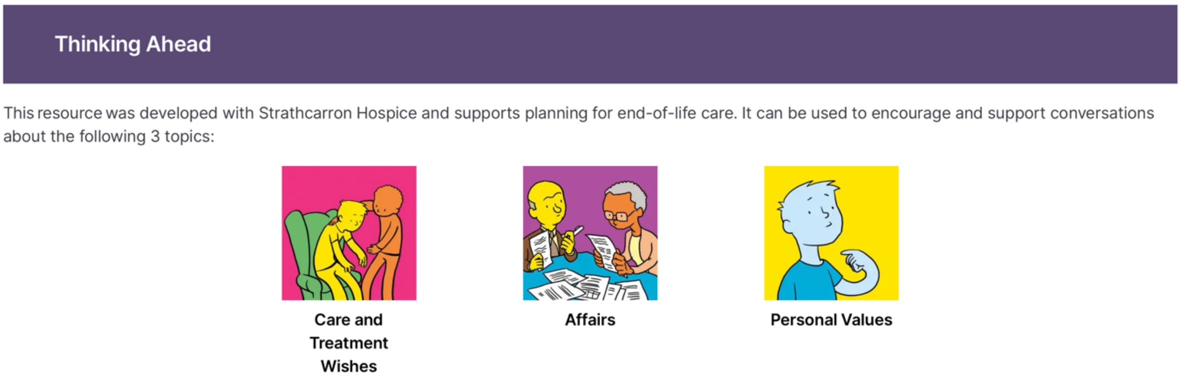
'Talking to your Doctor' is made by:

Ruth Koops van 't Jagt - University of Groningen
Ype Driessen - Fotostrips.nl

irohla
innovative policies for healthy ageing

IROHLA received funding from the European Union's Seventh Framework Programme under grant agreement n°305831

Appendix 5.10 Talking Mats resource
(Example from website, full link below)

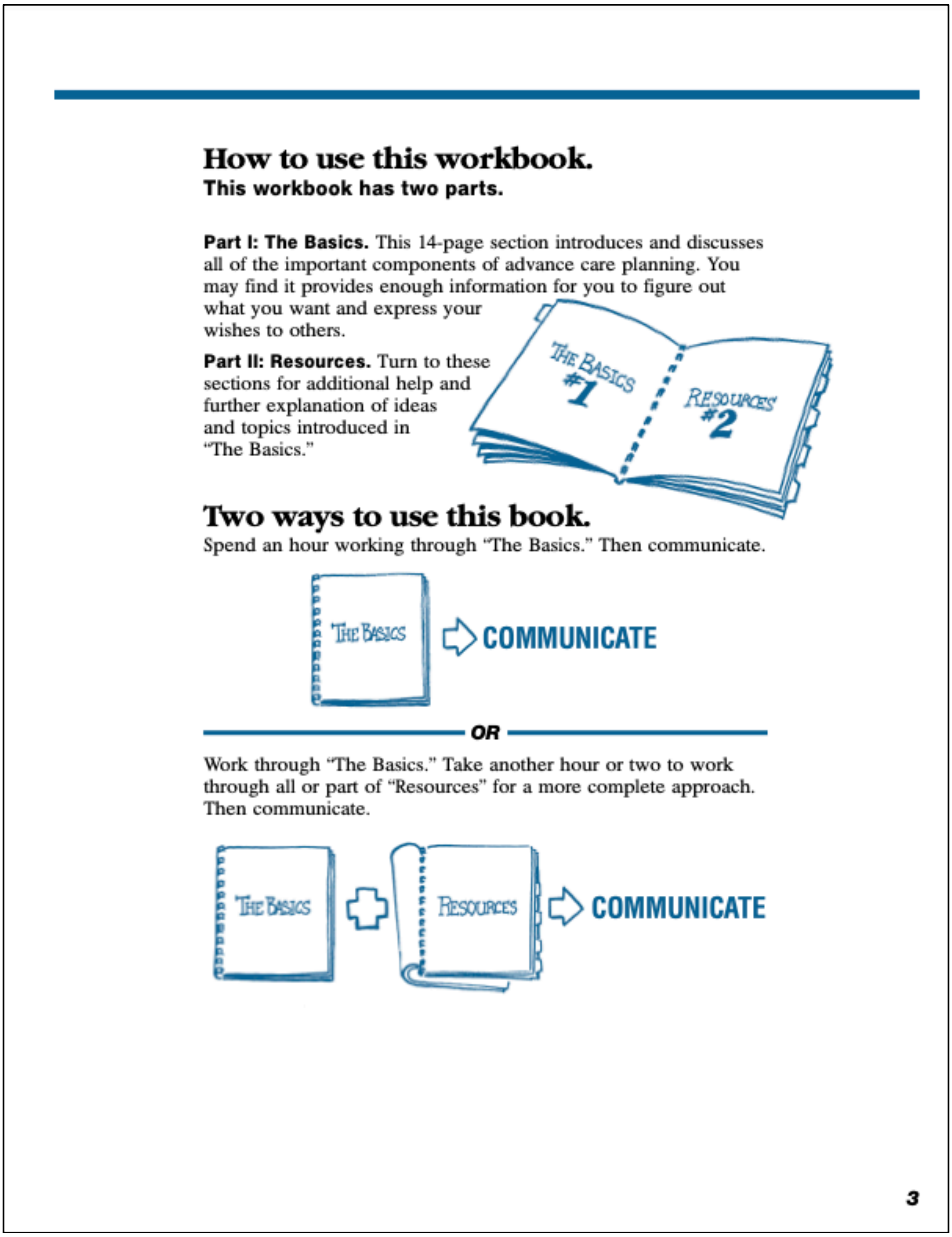


Thinking Ahead

This resource was developed with Strathcarron Hospice and supports planning for end-of-life care. It can be used to encourage and support conversations about the following 3 topics:

https://www.talkingmats.com/about/our-resources/

Appendix 5.11 Your Life, Your Choices resource
(Example from workbook, full link below)



How to use this workbook.

This workbook has two parts.

Part I: The Basics. This 14-page section introduces and discusses all of the important components of advance care planning. You may find it provides enough information for you to figure out what you want and express your wishes to others.

Part II: Resources. Turn to these sections for additional help and further explanation of ideas and topics introduced in "The Basics."

Two ways to use this book.

Spend an hour working through "The Basics." Then communicate.

OR

Work through "The Basics." Take another hour or two to work through all or part of "Resources" for a more complete approach. Then communicate.

3

https://www.endoflifeplanners.com/wp-content/uploads/2023/08/Your_life_your_choices.pdf

Appendix 7.1 Medical Research Council reporting guidelines checklist

Checklist for developing and evaluating complex interventions
This checklist is intended as a tool to help researchers prepare funding applications, research protocols and journal publications. It may also help reviewers to assess whether or not the recommendations have been followed.

Item	If NO, please justify. If YES, briefly describe how this has been addressed	Reported on page number(s)
Addressing uncertainties		
Have you determined the aim(s)/purpose(s) of the intervention?	Yes	205
Have you identified the key uncertainties given existing evidence about the intervention and the context in which it will be tested or implemented?	Yes	200
Do the research questions and methods address the key uncertainties?	Yes	198-201
Does the choice of research perspective (efficacy, effectiveness, theory-based, systems) reflect the key uncertainties that have been identified?	Yes	205-209
Engaging stakeholders		
Have you engaged stakeholders in the design/identification of the intervention and the development of the research protocol?	Yes	217-225
Have you engaged stakeholders in the conduct of the research and the dissemination of findings?	Yes	221-225
Have all stakeholders declared any potential conflicts of interest?	N/A	
Considering context		
Have you identified all the dimensions of context that may influence how the intervention achieves its effects?	Yes	198-199
Have you considered how context may affect the scaling up or scaling out of the intervention?	Yes	226-236
Developing and refining programme theory		
Have you developed a programme theory for your intervention that describes the key components and mechanisms of the intervention and how it interacts with the context in which it will be implemented?	Yes	205-210
	Yes	205-210

Item	If NO, please justify. If YES, briefly describe how this has been addressed	Reported on page number(s)
Have you updated the programme theory to incorporate the new evidence gathered by the study?		
Refining the intervention		
Have you refined the intervention so that it is optimised for the context in which it will be implemented?	Yes	218-221
Have you specified how far and in what ways the intervention can be refined during implementation without undermining the programme theory?	N/A, to be addressed in next steps	
Economic considerations		
Have you considered whether or not the value of the evidence, in terms of informing future decision-making, justifies the cost of the research?	Yes	236
Have you identified an economic evaluation framework that is appropriate to the expected outcomes of the intervention?	N/A, to be addressed in next steps	
Phase-specific considerations		
Developing interventions – have you used a formal framework (such as INDEX) to guide development of the intervention?	Yes	
Identifying interventions – for policy and practice interventions, have you performed an evaluability assessment to determine whether or not and how an evaluation should be undertaken?	Yes	
Feasibility – have you defined and used clear progression criteria to guide decisions about whether to proceed to an evaluation study?	Yes	
Evaluation – have you chosen an appropriate study design to answer the research questions and provide robust evidence to inform decision-making about further intervention refinement, evaluation or implementation?	N/A	
Implementation – have constraints and enablers of implementation been considered at all phases, from intervention development, through feasibility and effectiveness testing, to large-scale roll-out?	N/A	

Appendix 7.2 Wider stakeholder event advertisement poster

The ENGAGE Study
Research Event
at Foxtroy House

Where
- Foxtroy House, Dining Room

When
- Wednesday 18th September
- 10:30-12:00

Who
- A care home resident and someone close to them who they would be happy to talk about research with (e.g., a relative, friend, or staff member)
- Brittany and Fiona will be there to help support you to talk about research

What
- Brittany and will come in and support you to talk about research
- Each pair will sit down together and talk about research. Questions and prompts will be given to help guide your conversations
- Tell us what you think!

Why
- We would like more care home residents to have the opportunity to take part in research
- This could help to improve care home residents' health care, social care, and quality of life
- We need your help to make this happen - by talking about research!

If you are able, please come along and help us to improve the inclusion of care home residents in research

Refreshments will be provided

If you would like any more information about the ENGAGE Study or the research event, please feel free to contact the lead researcher, Brittany Nocivelli:
Email: nocivellibe@cardiff.ac.uk
Twitter/X: BENocivelli

Appendix 7.3 Wider stakeholder event feedback form

CARDIFF UNIVERSITY PRIFYSGOL CAERDYDD

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

CARDIFF UNIVERSITY PRIFYSGOL CAERDYDD
Centre for Trials Research
Canolfan Ymchwil Treialon

Canolfan PRIME Cymru
Wales PRIME Centre

The ENGAGE Study
Research Event 18/09/2024

Feedback – Let's Talk Research Toolkit

Name of resident: ____ Name of relative/friend/staff member/other (if other, please state): ____

The Toolkit:

Let's Talk Research

We want to help you to talk about research

As a pair, here are some general questions worth considering

Be Courageous
What would happen if we gave this a go?

Consider Other Perspectives
What do others think?

Connect Emotionally
How does this make you feel?

Collaborate
How can we work together to make this happen?

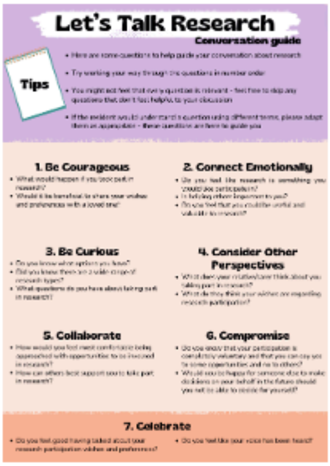
Be Curious
Help us to understand what is happening?

Compromise
What is real and possible?

Celebrate
What would work well?

The separate conversation guide has relevant prompt questions to help you navigate your conversation about research

1. **Shared handout**



Let's Talk Research
Conversation guide

Tips
- Here are some questions to help guide your conversation about research
- Try working your way through the questions in number order
- You might not feel that every question is relevant - feel free to skip any questions that don't feel helpful to your discussion
- If the resident would understand a question using different terms, please adapt them as appropriate - these questions are here to guide you

1. Be Courageous
- What would happen if you took part in research?
- Would it be beneficial to share your wishes and preferences with a loved one?

2. Connect Emotionally
- Do you feel the research is something you would like participate in?
- Is helping others important to you?
- Do you feel that you could be useful and valuable to research?

3. Be Curious
- Do you know what options you have?
- Did you know there are a wide range of research types?
- What questions do you have about taking part in research?

4. Consider Other Perspectives
- What does your relative/carer think about you taking part in research?
- What do they think your wishes are regarding research participation?

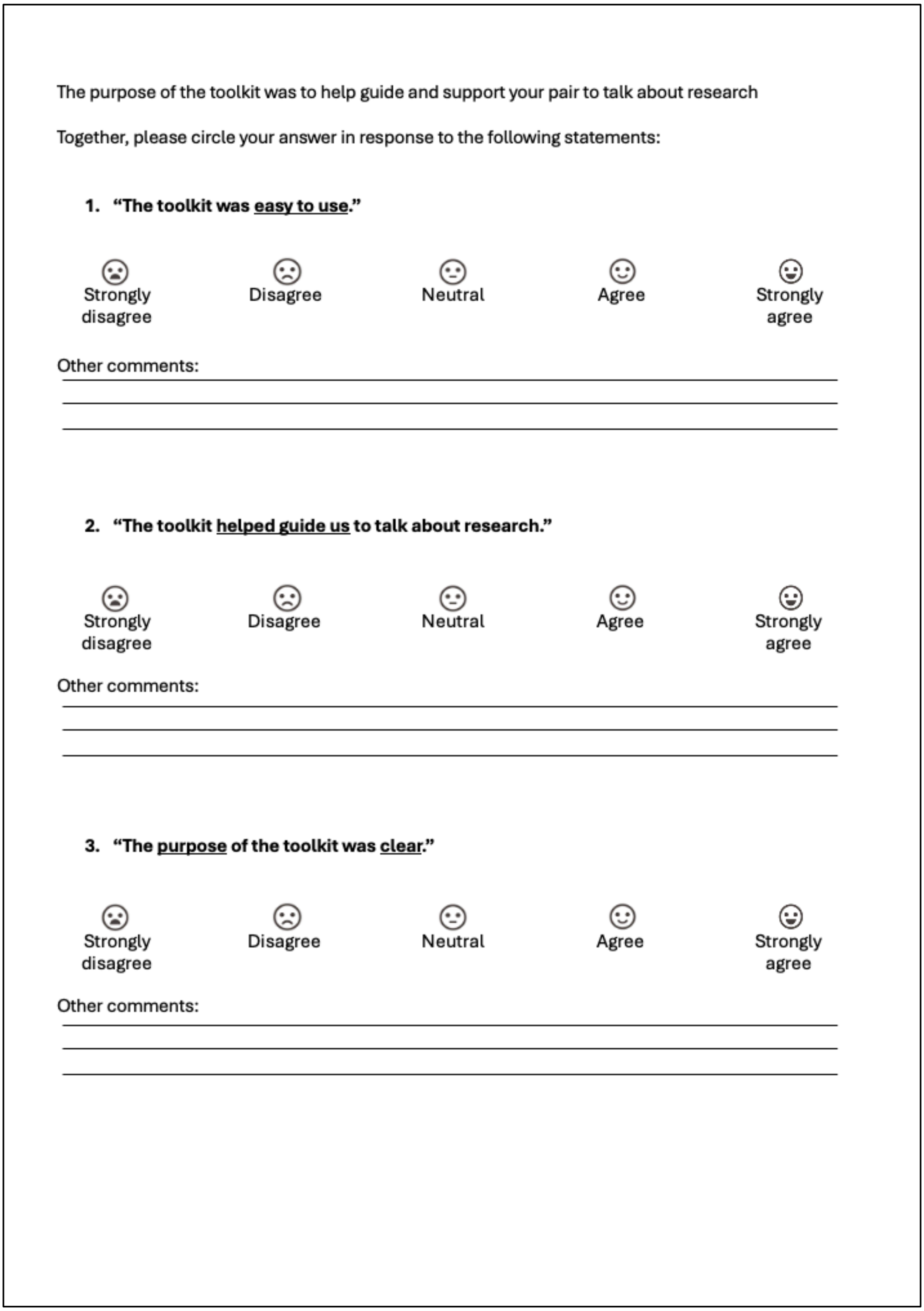
5. Collaborate
- How would you feel most comfortable being approached with opportunities to be involved in research?
- How can others best support you to take part in research?

6. Compromise
- Do you know that your participation is completely voluntary and that you can say yes to some opportunities and no to others?
- Would you be happy for someone else to make decisions on your behalf in the future should you not be able to decide for yourself?

7. Celebrate
- Do you feel good having talked about your research participation wishes and preferences?
- Do you feel like your voice has been heard?

2. **Conversation guide**

3. **Visual aids**



The purpose of the toolkit was to help guide and support your pair to talk about research

Together, please circle your answer in response to the following statements:

1. **"The toolkit was easy to use."**

😧 Strongly disagree	☹ Disagree	😐 Neutral	🙂 Agree	😀 Strongly agree

Other comments:

2. **"The toolkit helped guide us to talk about research."**

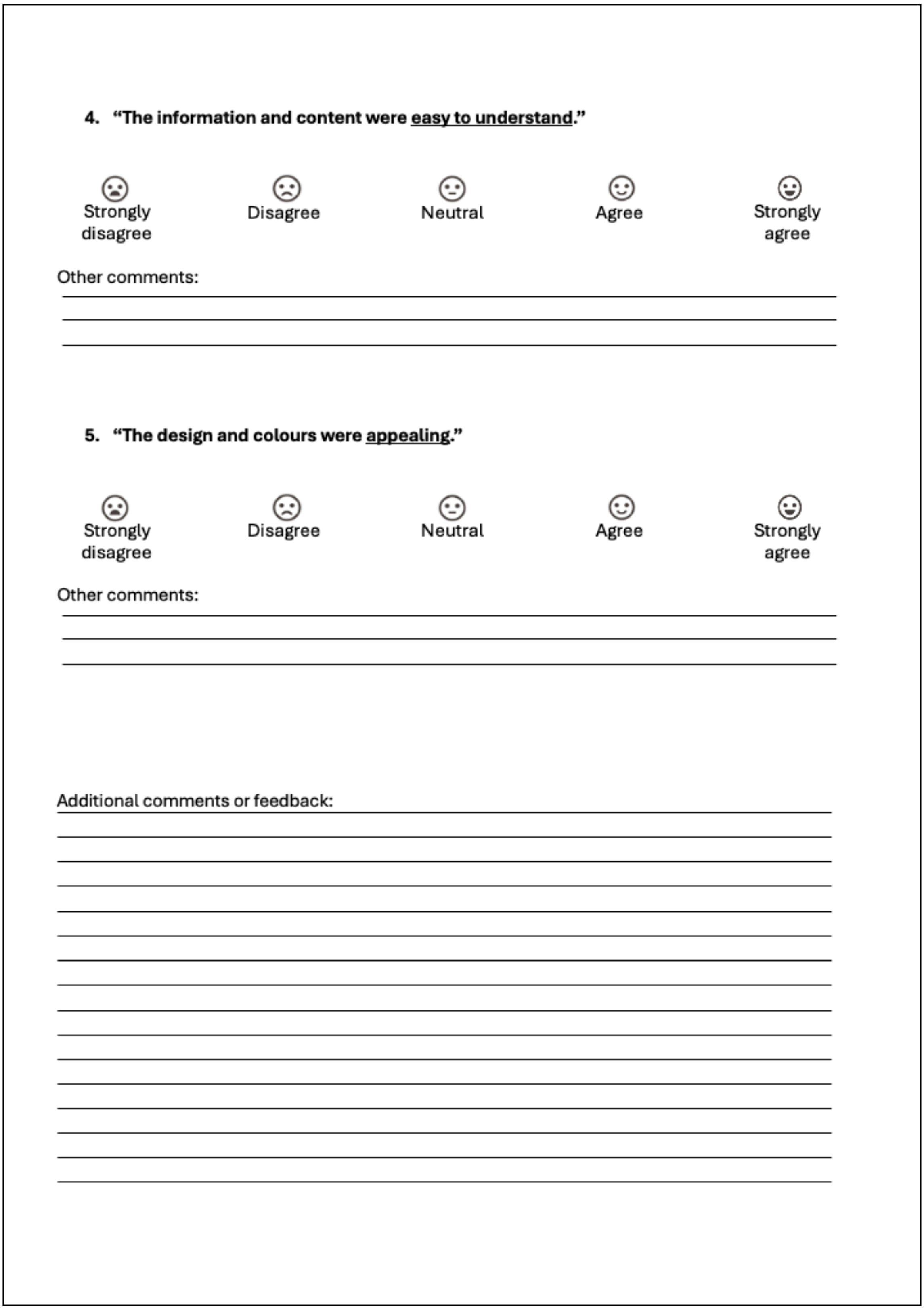
😧 Strongly disagree	☹ Disagree	😐 Neutral	🙂 Agree	😀 Strongly agree

Other comments:

3. **"The purpose of the toolkit was clear."**

😧 Strongly disagree	☹ Disagree	😐 Neutral	🙂 Agree	😀 Strongly agree

Other comments:



4. "The information and content were <u>easy to understand</u>."

Strongly disagree	Disagree	Neutral	Agree	Strongly agree

Other comments:

5. "The design and colours were <u>appealing</u>."

Strongly disagree	Disagree	Neutral	Agree	Strongly agree

Other comments:

Additional comments or feedback:

Appendix 7.4 Pictures taken at the wider stakeholder event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