

# Realist informed mixed-methods evaluation of cancer rehabilitation services in South Wales

A thesis submitted in partial fulfilment of the requirements of  
Cardiff University for the degree of Doctor of Philosophy

2021

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# Summary

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**Background:** Cancer rehabilitation, which can comprise exercise and dietary advice among other interventions depending on people's needs, has been found to improve quality of life worldwide. However, in Wales, 41.3% of Welsh Cancer Survey respondents reported receiving no or limited support with their rehabilitation needs. The reasons for this insufficient support are uncertain. The broad aim of this study was to investigate what works in two cancer rehabilitation services, for whom, in what circumstances and how.

**Methods:** Realist evaluation (RE) informed the study design, as RE seeks to answer the question of what works, for whom, in what circumstances and how with the development of context-mechanism-outcome (CMO) configurations. Based on RE principles, first four initial cancer rehabilitation theories were developed through literature review and consultation with experts. The initial theories were tested with mixed methods: quantitative secondary analysis of routine cancer rehabilitation data; and qualitative, one-on-one, semi-structured interviews (n=35) with healthcare professionals and people with cancer.

**Findings:** Testing the four initial theories which focused on information provision, healthcare professionals' training, individualised care, and cancer rehabilitation interventions showed that services did not always work as hypothesised. Numerous contexts inhibited information provision, healthcare professionals' training and cancer rehabilitation, for example, the medical model, healthcare professionals' lack of time, accessibility concerns, and insufficient needs assessment, leading to fluctuations in service uptake, staff capacity issues and people's unmet health needs. Moreover, professional boundaries were identified as mechanisms influencing cancer rehabilitation provision. However, well managed therapeutic relationships, family and "spontaneous" peer support aided the provision of individualised, tailored cancer rehabilitation interventions resulting in people's improved quality of life and self-management.

**Conclusion:** Cancer rehabilitation services in South Wales have the potential to help people cope with cancer and improve quality of life. However, several contexts hinder service provision, which needs addressing for optimal cancer rehabilitation.





## Acknowledgements

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I would like to express my deepest gratitude to my supervisors, Dr Tessa Watts and Dr Dominic Roche. Thank you for your endless support and faith in me, I could not have done this without your guidance.

I would like to thank Professor Deborah Fitzsimmons for her support and guidance at the beginning of this PhD journey, and Dr Mari Jones for the statistical support throughout this PhD study. Thank you! You both helped me grow as a researcher.

I would like to thank my colleagues, and my manager, Professor Jane Hopkinson. Thank you for listening to me and helping me develop ideas.

I would like to express my gratitude to Macmillan Cancer Support, Swansea University, and Cardiff University's John and Alice Edwards Studentship Fund for the scholarship that enabled me to embark on this journey. I would like to express my utmost gratitude to the Steering group of this study. Thank you ever so much for your help, input, and guidance in the development of this PhD study, and for your support throughout the years.

I am grateful for the help and support of the Willow and Fern Therapy Teams in the recruitment of people affected by cancer for the qualitative interviews. I am forever indebted to you. Moreover, I would like to thank all healthcare professionals within these teams who participated in the interviews. Your insight and experiences were really valuable. I would also like to thank every person who decided to share their cancer experiences with me. This PhD study could not have happened without your contribution. I am proud to represent your voices.

I am grateful for my family, for the endless love and support of my parents, Gyöngyi and Imre. I would like to thank my brother, Péter and his family, Gabi and Judit, who sow the seed years ago that I should pursue a career in research. I would like to thank my friends who stuck to me even though I disappeared sometimes to focus on my research. I would like to thank Brian for reading my last few chapters and providing invaluable help.

Finally, I would like to thank the best person I know for his pestering, love and support throughout this PhD journey. Thank you for putting up with me during lockdown while

writing my thesis. I could not have done this without you. I love you Jonathan. You are the best.

## Publications and presentations arising from this thesis

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1. Csontos, J.K. et al. 2021. Perspectives on cancer rehabilitation in South Wales, UK: qualitative investigation of experiences of people affected by cancer and healthcare professionals. Presented at: *International Conference for Cancer Nursing 2021 Virtual conference*, 2-5 February 2021.
2. Csontos, J.K. et al. 2021. Secondary analysis of routinely collected cancer rehabilitation data from a specialist service in South Wales, UK. *International Conference for Cancer Nursing 2021 Virtual conference*, 2-5 February 2021.
3. Csontos, J.K. et al. 2020. Exploring cancer rehabilitation services in South Wales: qualitative understanding from the perspectives of people affected by cancer and healthcare professionals. *Physiotherapy* 107 (S1), E32-E33. doi: 10.1016/j.physio.2020.03.046.1016/j.physio.2020.03.046
4. Csontos, J.K. et al. 2019. Qualitative exploration of cancer rehabilitation in South Wales, UK from the perspectives of people affected by cancer and healthcare professionals. Presented at: *National Cancer Research Institute Conference*, Glasgow, UK, 3-5 November 2019.
5. Csontos, J.K. et al. 2019. Secondary analysis of routinely collected data from a specialist cancer rehabilitation service in South Wales, UK. Presented at: *National Cancer Research Institute Conference*, Glasgow, UK, 3-5 November 2019.
6. Csontos, J.K. et al. 2019. Exploring cancer rehabilitation services in South Wales: a qualitative understanding from perspectives of people affected by cancer and healthcare professionals. Presented at: *Physiotherapy UK 2019*, Birmingham, UK, 1-2 November 2019.
7. Csontos, J.K. et al. 2019. Barriers and facilitators to cancer rehabilitation services in South Wales, UK: Perspectives of oncology healthcare professionals. Presented at: *RCN International Nursing Research Conference*, Sheffield Hallam University, UK, 3-5 Sep 2019.
8. Csontos, J.K. et al. 2019. Realist evaluation of cancer rehabilitation services in South Wales (REEACaRS): a mixed methods study protocol. *BMJ Open* 2019;9:e025953. doi: 10.1136/bmjopen-2018-025953
9. Csontos, J.K. et al. 2018. The perception and operation of cancer rehabilitation services in South Wales from healthcare professionals' perspective: a qualitative study. Presented at: *Crossing Boundaries in Cancer Care UKONS Annual Conference 2018*, Glasgow, 16-17 November 2018.

## Abbreviations

Abbreviation	Term	Abbreviation	Term
AHP	Allied health professional	GP	General Practitioner
AMED	Allied and Complementary Medicine	GRS	Graphic rating scale
ASSIA	Applied Social Sciences Index & Abstracts	HCPC	Health and Care Professions Council
CASP	Critical Appraisal Skills Programme	HNA	Holistic needs assessment
CDP	Cancer Delivery Plan	HRA	Health Research Authority
CMO	Context-Mechanism-Outcome	HRT	Hormone replacement therapy
CNAG	Cancer Network Advisory Group	IBM SPSS	International Business Machines Statistical Package for the Social Sciences
CNS	Central nervous system/cancer nurse specialist (indicated in the text)	ICC	Intraclass correlation
COP	Centre of Pressure	IPT	Initial Programme Theory
COPD	Chronic obstructive pulmonary disease	M	Mean
DC_CODE	Discharge code	MAR	Missing at random
DNA	Did not attend	MCAR	Missing completely at random
ECR	Enhanced Cancer Recovery	MCID	Minimal Clinically Important Difference
EDGE Task Force	Evaluation Database to Guide Effectiveness Task Force	Mdn	Median
EONS	European Oncology Nursing Society	MDT	Multidisciplinary team
FACIT-F	Functional Assessment of Chronic Illness Therapy – Fatigue	MNAR	Missing not at random
FACT	Functional Assessment of Cancer Therapy	MOS SF-20	Medical Outcomes Study Short Form-20
GCP	Good Clinical Practice	MSCC	metastatic spinal cord compression
GI	Gastrointestinal	n	Number

<b>Abbreviation</b>	<b>Term</b>	<b>Abbreviation</b>	<b>Term</b>
NCAT	National Cancer Action Team	RCT	Randomised control trial
NCRI	National Cancer Research Institute	RSCL	Rotterdam Symptom Check-List
NHS	National Health Service	SGM	Steering Group Member
NICE	National Institute for Health and Care Excellence	SLT	Speech and language therapist
NRS	Numeric rating scale	SOB	Shortness of Breath
NVC	No valid cases	TUAG	Timed Up and Go Test
OT	Occupational therapist	UK	United Kingdom
OT121	One-to-one OT sessions	USA/US	United States of America
PADR	Personal Appraisal and Development Review	VAS	Visual analogue scale
POMS	Profile of Mood States	VRS	Verbal rating scale
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses	WCPES	Welsh Cancer Patient Experience Survey
PROM	Patient Reported Outcome Measure		
PSA	Prostate-Specific Antigen		
PT121	One-to-one physiotherapy sessions		
QOL	Quality of life		

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# Chapter 1: Introduction

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This chapter aims to introduce the thesis and both the policy and clinical setting in which this PhD research is located. The chapter begins with a brief overview of cancer in the UK, specifically incidence, and the impact of cancer and its treatments on individuals. Then the key policy drivers and guidance shaping the development of cancer rehabilitation in Wales and gaps in service provision are considered. The development of this PhD study is then described, and the research aims presented. Finally, an outline of this PhD thesis<sup>1</sup> is provided.

## 1.1 Cancer in the United Kingdom and Wales

The number of people diagnosed with cancer in the United Kingdom (UK) is growing. In 2018, it was estimated that approximately 367,000 people were diagnosed with cancer UK-wide, with Wales accounting for over 19,000 cases (Welsh Cancer Intelligence and Surveillance Unit 2019). In addition, a 2% increase is expected in new cases every year (Cancer Research UK 2018). With continuing developments in cancer screening and treatments, more people are living with and beyond cancer. It was estimated that around 2.9 million people lived with a cancer diagnosis in 2020 UK wide, and 160,000 people in Wales (Macmillan Cancer Support 2019b). It is expected that by 2030, 4 million people will be living with a cancer diagnosis in the UK, and 220,000 people in Wales (Macmillan Cancer Support 2019b).

Regardless of the advances in screening and treatments, a cancer diagnosis can have life altering consequences. These consequences are often referred to as long-term and late effects (Rowland et al. 2020).<sup>2</sup> These two effects are often considered as one (Macmillan Cancer Support 2019a), although they can be defined as two separate conditions. Long term effects are health issues that develop during treatment and can have lasting impact even 5 years after finishing treatments (Rowland et al. 2020, Stein et al. 2008). Long-term effects impact on both physical and psychological health, and issues include fatigue, mobility problems, pain, breathlessness, malnutrition, depression and anxiety (Stein et al.

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<sup>1</sup> The terms PhD thesis, PhD study or PhD research are used interchangeably throughout this thesis.

<sup>2</sup> Throughout this PhD thesis cancer and treatment related consequences might be referred to as “long-term and late effects” or “treatment related side effects” interchangeably.

2008; National Cancer Action Team 2013). Late effects are defined as physical or psychological health problems that present 6 months or later post treatments and could affect whole organ systems as a consequence of cancer treatments (Rowland et al. 2020, Stein et al. 2008). Examples of late effects include cardiovascular toxicities, reduced bone density, or hypothyroidism (Stein et al. 2008, Kenyon et al. 2014). There is a gap in the evidence base on how many people are affected by long-term and late effects, although Macmillan Cancer Support (2013a) estimated in 2013 that approximately 500,000 people UK-wide had health issues post treatment. This number is expected to have increased. In addition, Macmillan Cancer Support (2015) surveyed and interviewed people affected by cancer UK-wide regarding their social and emotional care needs and found that 64% of respondents (n=1037) had practical support needs, such as mobility, personal care, or looking after dependants. Furthermore, 78% of respondents (n=1037) needed emotional support after diagnosis.

The National Institute for Health and Care Excellence (NICE 2004) defined cancer rehabilitation as a service which helps people achieve maximal functioning, independence and adaptation to changes caused by cancer and its treatments. There is growing evidence that cancer rehabilitation can provide help and support with long-term and late treatment effects and improve health-related quality of life (Hunter et al. 2017a, b; Stout et al. 2017; Peddle-McIntyre et al. 2019). Cancer rehabilitation can embody a wide range of interventions, including physical exercise, dietary advice, speech and language therapy, psychological support (for example, counselling, mindfulness, cognitive behavioural therapy), and health education, among others. Physical, psychological, and educational elements combined are often referred to as multidimensional cancer rehabilitation (Scott et al. 2013).

In Wales, cancer rehabilitation and support services have been provided in various formats over the years. Exercise classes, health education and information courses, or counselling sessions have been provided by the National Health Service (NHS) and/or third sector organisations (Velindre Cancer Centre 2013, Welsh Government 2014, 2015). The next section of this chapter explores the policies and guidance which have shaped cancer rehabilitation service provision in Wales.

## 1.2 Key policy drivers and guidance for cancer rehabilitation services in Wales

To understand cancer rehabilitation provision in Wales, it is important to identify and explore the key policies and guidance that have shaped services. Before 1<sup>st</sup> July 1999, responsibility for the NHS in Wales lay with UK Government via the Welsh Office (Michael and Tanner 2007). In the aftermath of the 1997 devolution referendum, all governing powers were transferred to the Welsh Government (Michael and Tanner 2007). Organisational controls and health service provision is dealt with by the Welsh Government, enabling Wales to develop its own health policies and guidance (Michael and Tanner 2007). Therefore, it is important to discuss cancer rehabilitation in the context of Welsh health policies and guidance. However, regardless of devolution, certain UK wide guidance, such as the NICE (2004) guidance, still influences service provision in Wales. Wales and UK-wide policies influencing cancer rehabilitation are presented in Table 1.

While the concept of cancer rehabilitation first emerged in 1969 in the USA (Dietz 1969), strategic direction and implementation in the UK has been slow. Table 1 below shows that rehabilitation services for people affected by cancer were first considered as part of the national cancer care agenda in 1995 (Expert Advisory Group on Cancer 1995). Often referred to as the Calman-Hine report, was the first document to mention cancer rehabilitation services. However, clear recommendations on cancer rehabilitation service development did not emerge until 2004, when the NICE (2004) guidance on supportive and palliative care in cancer was published in response to the recognition that people affected by cancer often had unmet supportive and rehabilitative needs during and after treatments. Invariably, this was a consequence of: insufficient information on supportive and rehabilitative services; unsatisfactory knowledge and understanding of rehabilitation and supportive care in cancer among healthcare professionals; inaccessible services; problems with care coordination and staff capacity and deficient facilities and equipment for service provision (NICE 2004).

Table 1 Summary of key policy and guidance milestones shaping cancer rehabilitation in Wales

Key policy documents and guidance shaping cancer rehabilitation in Wales
<p>1995. Expert Advisory Group on Cancer. 'A Policy Framework for Commissioning Cancer Services' (Calman-Hine Report)</p> <p><b>Aim:</b> To create a uniformly high-quality network of cancer care in England and Wales.</p> <p><b>Recommendation:</b> Cancer units and centres should have integrated cancer rehabilitation services or should have clear referral routes to cancer rehabilitation close to the person's home.</p> <p>1996. Cancer Services Expert Group. 'Cancer Services in Wales' (Cameron report)</p> <p><b>Aim:</b> To review cancer services and describe the ideal high-quality care.</p> <p><b>Recommendation:</b> Cameron report mainly focused on improving screening and treatment and only mentioned that rehabilitative and supportive services should be provided in the cancer services.</p> <p>2004. NICE. 'Improving Supportive and Palliative Care for Adults with Cancer'</p> <p><b>Aim:</b> To define supportive, palliative, and rehabilitative service models to help people and their families cope with cancer and its treatments.</p> <p><b>Recommendation:</b> Four level model should be used as the rehabilitation service delivery model. Rehabilitation should be based on needs assessment with a Cancer Network wide assessment tool.</p> <p>2005. Welsh Government. 'National Standards for Cancer Services'</p> <p><b>Aim:</b> To define the core attributes of cancer services that should be provided throughout Wales. National Standards are cancer site specific.</p> <p><b>Recommendation:</b> National Standards described the cancer service organisation, patient-centred care, the multidisciplinary team, the assessment and treatment of people affected by cancer.</p> <p>2006. Welsh Government. 'Designed to Tackle Cancer in Wales'</p> <p><b>Aim:</b> To guide cancer service and care quality improvements.</p> <p><b>Recommendation:</b> It addressed issues with cancer rehabilitation in Wales, namely: planning and co-ordination.</p> <p>2010. Welsh Government. 'National Standards for Rehabilitation of Adult Cancer Patients'</p> <p><b>Aim:</b> To define the core attributes of cancer rehabilitation services in Wales.</p> <p><b>Recommendation:</b> Organisation should be regulated by the Cancer Network Advisory Group (CNAG). Workforce should be arranged based on the four level model. Referral pathways should be developed by the CNAG.</p> <p>2012. Welsh Government. 'Together for Health – Cancer Delivery Plan: A Delivery Plan up to 2016 for NHS Wales and its Partners' (CDP)</p> <p><b>Aim:</b> To provide a framework for action by University Health Boards and NHS Trusts to achieve excellent care, improved health, service quality and safety.</p> <p><b>Recommendation:</b> Needs assessment post treatment by key workers. CDP promoted collaboration between NHS Wales and third sector organisations to meet people's needs.</p> <p>2013. National Cancer Action Team (NCAT). 'Cancer Rehabilitation. Making excellent cancer care possible.'</p> <p><b>Aim:</b> To raise awareness and understanding of cancer rehabilitation amongst healthcare commissioners and providers.</p> <p><b>Recommendation:</b> Map rehabilitation needs of local population; maximise resources; focus on outcomes; understand rehabilitation services.</p> <p>2013. Aylward et al. (Bevan Commission) 'Simply Prudent Healthcare – achieving better care and value for money in Wales – discussion paper.'</p> <p><b>Aim:</b> To support more efficient ways of working in times of austerity.</p> <p><b>Recommendation:</b> People and clinicians co-produce health and wellbeing. Prioritise people with the greatest need. Clinicians should only provide care that is needed. Reduce inappropriate variance in care by using consistent practices based on up-to-date scientific evidence.</p> <p>2016. Welsh Government. 'Cancer Delivery Plan for Wales 2016-2020' (CDP)</p> <p><b>Aim:</b> To update the delivery plan and provide improved framework for cancer service provision.</p> <p><b>Recommendation:</b> It highlighted the role of rehabilitation from diagnosis until the end of life. This was the first document explicitly mentioning three phases of rehabilitative care: prehabilitation; care in acute oncology services; and rehabilitation after treatment.</p>

To support meeting people's needs, the NICE (2004) guidance recommended that a wide variety of cancer rehabilitation interventions should be offered to people affected by cancer, based on their individual needs. Therefore, needs assessment should be provided prior to or upon referral to cancer rehabilitation services. The NICE (2004) guidance also suggested the use of a standardised assessment tool across care settings. The standardised assessment tool should include the following health and wellbeing domains: nutritional status, mobility, self-care, oral health, coping at home, work, and leisure activities (NICE 2004). Moreover, the NICE guidance made recommendations on the workforce, and listed a variety of healthcare professionals, who should provide cancer rehabilitation, namely: dietitians, lymphoedema practitioners, occupational therapists (OTs), physiotherapists, psychosexual counsellors, speech and language therapists (SLTs), stoma therapists, and therapeutic radiographers among many other professions. In addition, the NICE (2004) guidance made recommendations on the model of cancer rehabilitation provision. The recommended four level model, detailed in Table 2, emphasises that rehabilitation should be every healthcare professional's responsibility. Furthermore, non-specialist therapists, nurses and technicians should be able to provide basic health information, which would help increasing the capacity of specialist services, who would focus on complex cases, matching their expertise.

The publication of the NICE (2004) guidance boosted cancer rehabilitation developments, leading to the establishment of the National Cancer Action Team (NCAT) in 2007 (National Cancer Action Team 2013b). NCAT aimed to improve cancer rehabilitation services by providing evidence and tools for commissioners and NHS clinicians to establish rehabilitation (National Cancer Action Team 2013b). In addition, the publication of the NICE guidance facilitated the development of national cancer rehabilitation standards for the devolved health services in England in 2008 and Scotland in 2007 (Welsh Assembly Government 2010). However, developments in Wales were slower, with the "National Standards for Rehabilitation of Adult Cancer Patients" published in 2010. The reason for this delay between Wales and other parts of the United Kingdom is unknown. However, it is possible that NHS Wales focused on the publication of the site-specific National Standards which were first published in 2005 with additional cancer site guidance, for example sarcoma added in 2009 (Welsh Assembly Government 2009).

The "National Standards for Rehabilitation of Adult Cancer Patients" (Welsh Assembly Government 2010) provided guidance on service organisation, workforce and the cancer



rehabilitation care pathway. Based on these National Standards, cancer rehabilitation organisation in Wales should be regulated by the Cancer Network Advisory Group (CNAG). CNAG is an assembly of lead healthcare professionals from their respective University Health Boards. Moreover, the National Standards adopted the use of the four level model from the NICE (2004) guidance.

Table 2 The four level model (NICE 2004, Welsh Assembly Government 2010)

Level	Rehabilitation need example	Group providing input	Assessment	Intervention
1	<ul style="list-style-type: none"> <li>• Simple energy conservation techniques</li> <li>• Simple or first line dietary advice</li> <li>• Advice to patients regarding skin care and risks of developing lymphoedema</li> </ul>	<ul style="list-style-type: none"> <li>• Patients and carers</li> <li>• General nursing staff</li> <li>• Therapeutic radiographers</li> <li>• Assistant practitioners/ support workers</li> </ul>	Recognition of needs for help and support based on assessment of function.	Basic interventions including self management and care strategies initiated by non-specialist healthcare professionals.
2	<ul style="list-style-type: none"> <li>• Post-operative physiotherapy following breast surgery.</li> <li>• Dietary advice for patients receiving enteral feeding</li> </ul>	Non-specialist AHPs	Routine assessment of rehabilitation needs.	Interventions provided for commonly presenting rehabilitation needs - post-operative input plus management of commonly presenting side effects of treatment or functional impairment.
3	<ul style="list-style-type: none"> <li>• Post-operative physiotherapy following breast surgery.</li> <li>• Dietary advice for patients receiving enteral feeding</li> </ul>	Experienced AHPs with basic level training in cancer rehabilitation working at senior level.	Specialist assessment from an experienced AHP.	Interventions provided by professionals with knowledge and experience of effects of cancer treatment and aetiology; interventions requiring knowledge of the impact of the disease.
4	<ul style="list-style-type: none"> <li>• Management of a patient with spinal cord compression.</li> <li>• Swallowing assessment for patients having had radical head and neck surgery.</li> <li>• Management of severe or complicated lymphoedema.</li> </ul>	Advanced Practitioner AHPs working predominantly or exclusively with patients with cancer and with higher training as specialist practitioners.	Highly specialist complex assessment from expert AHP	Highly specialist interventions for patients having radical surgery, patients with advanced disease, patients with functional impairment, patients undergoing combination therapies and/ or patients with complex end of life issues.

Following the publication the 'National Standards for Rehabilitation of Adult Cancer Patients', the next step in Wales tackling cancer was the publication of the Cancer Delivery Plan (CDP) in 2012, which set out objectives for NHS Wales up to 2016 (Welsh Government 2012). Increasing cancer incidence and survival rates motivated the Welsh Government to aim for improved prevention, earlier detection, fast and more effective treatments, meeting people's needs and more focus on end-of-life care. Rehabilitation service provision was mentioned in the new CDP as part of the goal of meeting people's needs. The CDP (2012) advised adherence to the National Standards for cancer rehabilitation (Welsh Assembly Government 2010). It also recommended people's needs assessment post treatment. The CDP (2012) suggested that needs assessment should be provided by a nominated cancer key worker, a healthcare professional who coordinates care and information provision with the consent of the person affected by cancer (NICE 2004). Moreover, the CDP promoted collaboration between NHS Wales and third sector organisations to meet people's needs. Examples to this collaboration at the time included Tenovus Cancer Support providing mobile lymphoedema services in the community, and Macmillan Cancer Support working with the Welsh Government on the Welsh Cancer Patient Experience Survey (WCPES) (Welsh Government 2012).

In 2013, NCAT published recommendations for rehabilitation commissioners and providers to support service development and high quality cancer care (National Cancer Action Team 2013a). This document is important, as it had input from both NHS England and NHS Wales, shaping services in both nations. Unfortunately, NCAT was disbanded in 2013, leading to a loss of leadership in the field of cancer rehabilitation (Hunt 2014). Robb and Davis (2015) argued that the UK wide reason for leadership and development issues regarding cancer rehabilitation was that healthcare provision was still based on a traditional medical model. The medical model was originally defined as a systematic method of diagnosis through standard medical procedures (Engel 1977). However, whilst often criticised for its paternalism with disregard to patient empowerment, the medical model also separates biological and psychological health, and focuses on disability rather than enablement (Engel 1977). For these reasons Robb and Davies (2015) suggested that healthcare should progress towards a more holistic approach and person-centred care. Person-centred care is conceptualised by The Health Foundation (2016) as care that is personalised, coordinated, and supports enablement while treating the person with dignity and respect.

In 2014 a new healthcare strategy, Prudent Healthcare was introduced for NHS Wales (Welsh Government 2016b). Prudent Healthcare aimed to put people at the heart of care and support more efficient ways of working in times of austerity (Addis et al. 2019). There are four main principles of Prudent Healthcare: people and clinicians co-producing health and wellbeing; prioritising people with the greatest need; clinicians only providing care that is needed; and reducing inappropriate variance in care by using consistent practices based on up-to-date scientific evidence (Aylward et al. 2013). Prudent Healthcare was a welcome policy for cancer rehabilitation professionals, as it could help drive a healthcare model change towards a more person-centred care through co-production (Welsh Government 2015a).

In 2016 at the end of the first CDP four-year cycle, a new CDP was published to set out aims and plans until 2020 (Welsh Government 2016a). In the new CDP more emphasis was put on supportive and rehabilitation services. Furthermore, the role of supportive care and rehabilitation from the point of diagnosis was highlighted. CDP 2016 was the first document explicitly mentioning three phases of supportive and rehabilitative cancer care: prehabilitation to prepare patients for cancer treatment; care in acute oncology services; and rehabilitation after treatment. The CDP addresses the need for post-treatment support, especially because of the growing number of people living with and beyond cancer. In 2019 the Welsh Government gave permission for the update of the 'National Standards for Rehabilitation of Adult Cancer Patients' (Wales Cancer Network 2020). As of writing this thesis, work is still ongoing on these Welsh cancer rehabilitation standards and a new long term cancer strategy which supersedes CDP 2016 is yet to be published.

In summary, cancer policies and guidance have shaped cancer rehabilitation since 1995. Key recommendations have been made regarding workforce, cancer rehabilitation service provision model, health needs assessment of people's health needs, and change in the strategic model of healthcare. However, issues with cancer rehabilitation leadership, and the ever pervading influence of the medical model have slowed the development of policies and guidance. The next section explores the WCPES and what the survey results indicate about cancer rehabilitation provision in Wales.

### 1.3 Welsh Cancer Patient Experience Survey (WCPES)

The Welsh Government has been working with Macmillan Cancer Support and the Picker Institute to map people's experiences with cancer services in Wales. Two experience surveys have been conducted, one in 2013 and a second in 2016. While direct questions about cancer rehabilitation were not asked, some of the questions focused on care received from physiotherapist or district nurses, and practical and emotional support. The responses to these questions indicate how satisfied people are with supportive and rehabilitative services for people affected by cancer in Wales.

In 2013, 41% of WCPES respondents ( $n=3905$ ) who needed help from physiotherapists or district nurses reported that they had no (21%) or limited support (20%) with their needs (Welsh Government 2014b). In 2016, responses to the same question showed that 40.6% of respondents ( $n=3746$ ) who needed physiotherapy or district nurse help with their needs did not receive (21.2%) or had limited support (19.4%) (Welsh Government 2017). In addition, the 2016 WCPES had an extra question on practical advice and support. Responses indicated that 41.3% of participants ( $n=5994$ ) who need practical advice and support (advice on exercise, diet, or symptom management) received no (14.5%) or limited care (26.8%). These WCPES results show that people did not always receive the information or practical support needed (Welsh Government 2014b,2017). However, reasons for this lack of support has not been fully investigated in Wales.

### 1.4 The development of the PhD study

Having trained as a physiotherapist in Hungary, I worked for a local Hungarian Health Service in Rheumatology and Rehabilitation as a qualified physiotherapist. I was always curious to learn more and I wanted to use my knowledge to help improve healthcare. This hunger for knowledge and my passion for helping people were the motivation for starting my Master of Science (MSc) degree in physiotherapy in Wales. Completing my MSc dissertation made me realise that I would like to develop further as a researcher and this, coupled with my professional background and interest in rehabilitation, inspired me to apply for this Macmillan Cancer Support Funded PhD study. The main aim of the project was to investigate multidimensional cancer rehabilitation services in Wales.

There was a competitive application and interview process, and I was the successful applicant. I was enthusiastic to immerse myself in exploring cancer rehabilitation, which for me was a new ground. However, being from a physiotherapy background proved useful as the services I aimed to investigate were primarily assembled from physiotherapists and OTs. As a fellow physiotherapist I understood how interventions worked, but at the same time as an outsider to cancer rehabilitation I could look at the service more objectively than someone who came from an oncology background.

As soon as I started my PhD, I began scoping the literature to develop my knowledge of cancer rehabilitation and identify gaps in the evidence base. My initial literature searches revealed that there was growing evidence that cancer rehabilitation improved people's quality of life and helped them manage long-term and late treatment effects (Scott et al. 2013, Mishra et al. 2012). However, as previously mentioned in section 1.3 I also found that people in Wales do not always receive help and support with cancer-related health concerns when they need it and that reasons for this insufficient support have not been fully investigated. Consequently, I was keen to know why cancer rehabilitation services did not seem to work to their full potential in Wales.

The first puzzle piece of this PhD study was given in the shape of a routinely collected cancer rehabilitation database. This PhD project was developed with the support of the Willow Therapy Team<sup>3</sup> which provided a cancer rehabilitation service in South West Wales. The Willow Therapy Team had been routinely collecting outcome measure data from people affected by cancer who were referred to their service. People were asked to complete patient reported outcome measures (PROMs) before and after a rehabilitation episode. The Willow Therapy Team defined a rehabilitation episode as a 12-week long exercise programme based on the person's needs. Outcome measure data had been collected since 2014 with the aim of analysing it to show the impact of the service on people's quality of life and to make case for future service developments and funding applications. However, limited time and resources meant that they were unable to analyse the data. Therefore, one part of this PhD study was to use this routinely collected data to investigate cancer rehabilitation in South Wales. Using routinely collected data can provide rich information on service uptake and potential impact, making it useful for investigating

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<sup>3</sup> To keep confidentiality, the South West Wales cancer rehabilitation service is referred to as Willow Therapy Team throughout this PhD.

an implemented service and how it worked (Moen et al. 2017). However, the quantitative data in itself could not provide the depth that was needed to investigate potential barriers and facilitators of cancer rehabilitation services that resulted in the insufficient support reported in the WCPES (Welsh Government 2014b,2017). I decided that conducting qualitative interviews with cancer rehabilitation professionals and people affected by cancer who used the services could help explore the Willow Therapy Team in depth.

However, I thought that exploring one services may not fully capture why some people in Wales report insufficient support with needs and concerns during and after cancer treatments. Thus, to have a service as a comparison, I contacted the Fern Therapy Team<sup>4</sup>, a cancer rehabilitation service localised in South East Wales. With the investigation of the two services, I was able to cover a bigger geographical area and more people affected by cancer.

As I was able to include the two services in the investigation, I had to make a final decision on the methodological approach that would fit my research aims and objectives. I wanted to know the reason why some people had no or limited support with their cancer treatment related side effects. Moreover, both cancer rehabilitation services were implemented and established, and they used evidence-based interventions to improve the health and wellbeing of people affected by cancer. I understood that I had a chance to explore how cancer rehabilitation works locally and investigate services in their natural environment.

Developed by Pawson and Tilley (1997), realist evaluation is a methodological framework investigating how a service works for whom and in what circumstances. In contrast with experimental research designs, which are mostly interested in effectiveness, realist evaluation looks at the wider setting and the environment in which a service is implemented. This is important as the wider clinical, social, cultural, and political setting can have a real impact on the success of a service (Rycroft-Malone 2008). Therefore, realist evaluation principles were appropriate to guide the exploration of cancer rehabilitation barriers and facilitators that might have arisen from their setting.

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<sup>4</sup> To keep confidentiality, the South East Wales cancer rehabilitation service is referred to as Fern Therapy Team throughout this PhD.

#### 1.4.1 A brief introduction to realist evaluation

Realist evaluation is discussed in depth in chapter 4, although its key concepts are briefly introduced here, as they were important in the conceptualization of this PhD study. Realist evaluation is a theory-driven methodology, meaning that initial programme theories (IPTs) based on the underlying theoretical framework of the programme or service under investigation are set at the commencement of research. IPTs can be set via consultations with programme leads and developers, documentary analysis, and/or literature review (Pawson and Tilley 1997). These IPTs are later tested and refined with data collection and analysis (Pawson and Tilley 1997), often providing new theories and explanations on how a programme or service works, for whom and in what circumstances.

The unit of analysis in realist evaluation, which drives the research process, is context-mechanism-outcome (CMO) configurations (Pawson and Tilley 1997). Context refers to any influence that can support or inhibit a mechanism, including social and policy environment (Pawson and Tilley 1997). Mechanisms define how an intervention brings change and what response it triggers in the target populations' life (Pawson and Tilley 1997). Mechanisms can work differently in various contexts resulting in both expected and unexpected outcomes. Realist evaluators strive to create CMO configurations that best explain how interventions work.

#### 1.4.2 Study aims

The previous sections highlighted potential issues with cancer rehabilitation services in South Wales and introduced how this PhD study was developed leading to the aim of this thesis. A broad aim was set for this PhD to allow the development of relevant IPTs based on the literature and discussion with experts. The broad aim of this PhD study was to investigate what works in two cancer rehabilitation services, for whom, in what circumstances and how. The IPTs for this PhD study are discussed in chapter 4.

#### 1.4.3 Study setting

Cancer rehabilitation services (n=2) located in the two South Wales Cancer Centres were investigated. The inclusion of these two services enabled the investigation of how rehabilitation is provided in South Wales. Moreover, the exploration of two service models has the potential to represent the wide-ranging nature of cancer rehabilitation.

#### *1.4.3.1 Willow Therapy Team*

The Willow Therapy Team is situated in a University Health Board's Cancer Centre in South West Wales. This Team mainly sees people residing within the Health Board's area. However, occasionally provide care for another Health Board in South West Wales. The Willow Therapy Team provides inpatient and outpatient specialist OT, physiotherapy and rehabilitation services. Person-centred, individualised care is informed by findings from a modified version of the concerns checklist (Macmillan Cancer Support 2018). The Willow Therapy Team also collects PROMs to monitor change in people's quality of life and has been generating a database since 2014.

The outpatient rehabilitation programme is 12-weeks long, and the Willow Therapy Team refers to this 12-weeks programme as a 'rehabilitation episode'. A rehabilitation episode may include one-to-one sessions or group Tai-Chi, hydrotherapy and circuit classes depending on people's individual needs and goals. The group classes offer a gentle and an advanced option, allowing people more variety tailored to their needs, and a chance to progress to more challenging exercise groups. People affected by cancer can access the services directly through self-referral or can be referred by healthcare professionals at any point during the cancer rehabilitation pathway: diagnosis, treatment, post treatment or end-of life. The service has links to community and leisure activity providers, to assist people in accessing support closer to their home. The Willow Therapy Team has a strong emphasis on self-management support, which can be conceptualised in two ways: self-management support as a set of tools and techniques promoting healthy lifestyles among people affected by cancer; and self-management support as a collaborative relationship between caregivers and people affected by cancer (The Health Foundation 2011).

#### *1.4.3.2 Fern Therapy Team*

The Fern Therapy Team is based in a University NHS Trust, which is the cancer centre of South East Wales. As the main cancer centre in South East Wales, it oversees the cancer treatments of people coming from three different University Health Boards. The Fern Therapy Team mainly sees people during active treatments and following the end of treatments people are usually referred back to their local University Health Boards for more cancer rehabilitation.



Specialist inpatient and outpatient dietetics, speech and language therapy, OT and physiotherapy services are provided by the Fern Therapy Team. Health assessment of people affected by cancer is conducted on first contact with the Fern Therapy Team to provide goal-focused care which meets individuals' needs. Although it is not based on formal needs assessment, the service aims to support people remain as independent as possible from diagnosis until the end of life. Referral to rehabilitation is mainly via medical staff or other healthcare professionals. Outpatient services that are based on referral are: fatigue management group provided by the OT team; acupuncture provided by the physiotherapy team; and complementary therapies, such as reflexology. However, some outpatient services such as pilates classes and the dietetics drop-in clinic offer self-referral.

## 1.5 Thesis outline

This thesis is divided into eleven chapters within three main parts. The first part of this thesis focuses on setting the scene for this research. Following this introductory chapter, relevant literature is examined in chapters two and three. The middle part of the thesis focuses on the realist methodology and the methods chosen for this study. The last part of the thesis introduces the findings and discusses results in comparison to the literature and draws conclusions and key implications for practice and future research. Below the chapters and their content are briefly summarised.

**Chapter 2:** What is cancer rehabilitation? This chapter explores the cancer rehabilitation definitions using scoping review methodology. Common themes were derived from seventeen different cancer rehabilitation definitions, and the impact of having various definitions on people's perception of cancer rehabilitation is discussed.

**Chapter 3:** Barriers and facilitators of cancer rehabilitation – literature reviews from two perspectives: This chapter provides two reviews of the empirical literature regarding barriers and facilitators of cancer rehabilitation. To explore the barriers and facilitators of cancer rehabilitation in depth, original qualitative studies and qualitative synthesis papers from the perspective of people affected by cancer and healthcare professionals were reviewed.

**Chapter 4:** Realist evaluation: This chapter discussed the methodological framework of this PhD study in detail. A philosophical overview is provided and the key concepts of realist

evaluation by Pawson and Tilley (1997) are discussed further. Finally, the IPTs which are the realist hypotheses, are introduced.

**Chapter 5:** Secondary analysis methods: This chapter describes how the secondary analysis was conducted on the routinely collected outcome measure data.

**Chapter 6:** Qualitative interview methods: This chapter describes how qualitative data was collected from people affected by cancer and healthcare professionals. Sample size, recruitment, interview, and analysis procedures are presented in detail. Then, rigour in qualitative research and how it was ensured in this PhD study is discussed.

**Chapter 7:** Participants and data: This chapter introduces the participants who consented to be interviewed for this PhD study. Then the aspects of the routinely collected data is described, including the available data after cleaning the database, and the pattern of missing data.

**Chapter 8:** Information on and awareness of cancer rehabilitation services: This chapter discusses the findings of the realist evaluation related the first IPT.

**Chapter 9:** Healthcare professionals' training, professional boundaries, and the vicious cycle of time and staff: This chapter discusses the findings of the realist evaluation related to the second IPT.

**Chapter 10:** Individualised, tailored cancer rehabilitation: This chapter discusses the findings of the realist evaluation related to the third and the fourth IPT.

**Chapter 11:** Discussion and conclusion: The findings of this PhD study are critically discussed and compared to the literature. Then, limitations, reflection, recommendations for clinical practice, and future research are presented. Finally, the thesis is concluded.

## 1.6 Conclusion

In this introductory chapter, the key policies and guidance shaping cancer rehabilitation in Wales have been discussed and gaps in cancer rehabilitation provision identified. This influenced the aims and objectives of this PhD study. An overview of the study development has been provided and the research settings introduced. Finally, an outline of

the thesis as a whole has been presented. The next chapter explores the different definitions of cancer rehabilitation.

## Chapter 2: What is cancer rehabilitation?

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To investigate how cancer rehabilitation services work in South Wales, it is firstly necessary to understand the meaning of the term cancer rehabilitation. This is because definitions can contribute to people's perception of cancer rehabilitation. Using scoping review methodology, this chapter investigates how cancer rehabilitation has been defined in the literature. Firstly, the rationale for a scoping review is explained, the scoping review methodology used is then discussed and finally the review findings are presented.

### 2.1 Scoping review of cancer rehabilitation definitions

A scoping review of the literature is defined as knowledge synthesis that aims to map and clarify concepts and definitions, and identify evidence and research gaps in a specific area (Munn et al. 2018). It seeks to answer an exploratory research question by conducting literature search and synthesis systematically (Colquhoun et al. 2014). Therefore, this review method was chosen to investigate cancer rehabilitation definitions in the literature. However, scoping studies are a relatively new method of literature reviewing, and a lack of consistency in reported scoping reviews has been observed (Tricco et al. 2016). Arksey and O'Malley's (2005) six-point scoping review framework, refined by Levac et al. (2010) is frequently used. A Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist has recently been published to ensure scoping reviews are more rigorous, replicable and their findings are more generalizable (Tricco et al. 2018). To ensure the quality of this literature review, Tricco et al.'s (2018) PRISMA checklist and Arksey and O' Malley's (2005) framework were used, as seen in Table 3.

Table 3 Framework followed in this literature review

Six main stages of Arksey and O'Malley (2005) Scoping review framework
1. Identifying the research question
2. Identifying relevant studies
3. Study selection
4. Charting the data
5. Collating, summarizing, and reporting results
6. Consultation (optional)

## Framework stage 1: Identifying the research/review question

Establishing rehabilitation in cancer care started in the late 1960's with medical and rehabilitation professionals realising people were often left with debilitating symptoms and side effects after cancer treatment ended (Dietz 1969). Since then, cancer rehabilitation has had various definitions from solely medical, focusing on restoration to "normal" function (Fried 1975) to more inclusive interpretations considering psychological and social factors (Eckerdal 2017). However, there is no universally recognised and agreed definition of cancer rehabilitation (Garman and Jakobsson 2018).

Watson (1990) stated that the concept of cancer rehabilitation was hard to define and it needed recognition and direction. Wells (1990)<sup>5</sup> described how a review of rehabilitation at The Royal Marsden Hospital highlighted that one of the reasons behind inconsistent services was the lack of unified understanding of the cancer rehabilitation concept. Modern healthcare services are still struggling to provide support with people's cancer treatment related side effects, which might stem from the inconsistent perceptions of cancer rehabilitation.

Robb and Davis (2015) argues that rehabilitation is more accepted in other healthcare fields, such as neurology or musculoskeletal issues. This is supported by numerous accounts in the literature (Gunn 1984, Wells 1990, Watson 1992, Cheville 2007). In addition, people affected by cancer still often associate rehabilitation with physical exercise, which can impact on the service uptake (Silver et al. 2015). People whose needs are not only physical, might believe that rehabilitation is only about getting fit, which might result in people avoiding rehabilitation services and living with unmet health needs. This thesis aims to investigate the contexts in which cancer rehabilitation services work in South Wales. However, without investigating the definitions of cancer rehabilitation, it is almost impossible to understand why services are provided in their current form. Therefore, the aim of this literature review is to investigate how cancer rehabilitation is defined in the literature.

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<sup>5</sup> Richard J. Wells was the director of rehabilitation at The Royal Marsden Hospital in London from 1988 until 1993.

## Framework stage 2: Identifying relevant literature

To identify documents that provide definition of cancer rehabilitation, scientific and grey literature was scanned for relevance. Firstly, policy documents were searched to find definitions of cancer rehabilitation. NHS England and Wales, Welsh Government Cancer Plans and Department of Health Initiatives were scrutinized. Three library and electronic databases, namely: MEDLINE, CINAHL Plus and PsychINFO were systematically searched using search terms and their combinations as seen in Table 4. The following search limits were applied to this literature search: English language only, human research, adults, and adults over the age of 19. To allow the historical exploration of cancer rehabilitation definitions and how they evolved over time, no limits were placed on publication year. Boolean operators, such as AND, were used during the searches to narrow the number of records identified and exclude papers not relevant for this review.

Table 4 Terms and their combination used in electronic database searching

Search terms used for identifying the definition of cancer rehabilitation
Cancer AND rehabilitation AND definition
Cancer AND rehabilitation AND define
Cancer AND rehabilitation AND concept
"Cancer rehabilitation" AND definition
"Cancer rehabilitation" AND define
"Cancer rehabilitation" AND concept
"definition of cancer rehabilitation"
"concept of cancer rehabilitation"

Levac et al. (2010) state that literature selection is iterative, often involving several search strategies and refined search terms. In this literature review to ensure the full range of cancer rehabilitation definitions was identified, the Applied Social Sciences Index & Abstracts (ASSIA), Allied and Complementary Medicine (AMED), and Google Scholar databases were later searched. Moreover, the reference list of relevant papers and

documents retrieved were screened to identify potential publication containing cancer rehabilitation definitions not identified in electronic searches.

### Framework stage 3: Study selection

Following the completion of the literature searches, selection of eligible papers and documents started. Altogether 656 papers were identified through electronic searches and 35 documents through handsearching. As textbooks contained cancer rehabilitation definitions that were relevant for the aim of this review, these were included in this review. Scoping methodology does not require critical appraisal of the selected literature (Tricco et al. 2018). Therefore, inclusion of textbooks is acceptable and fits the aim of this literature review. After the removal of duplicates, 634 documents remained, and the selection process started. With books, relevant books sections were screened for cancer rehabilitation definitions. With research papers the titles, and abstracts were screened based on the following inclusion and exclusion criteria. After identifying the relevant literature, 39 full-text papers, documents and textbooks were scanned for eligibility in the study.

#### Inclusion criteria:

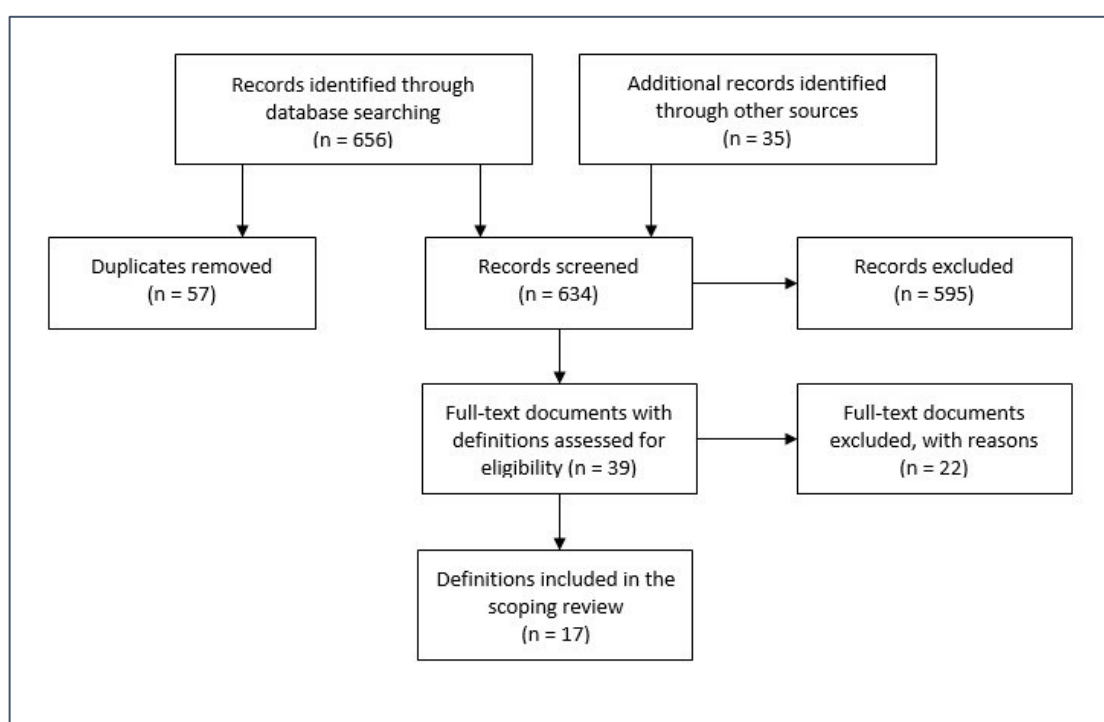
- Seminal works, reviews, guidelines, and books containing original cancer rehabilitation definitions that cannot be traced back to any other document.
- English language documents.
- Documents discussing the rehabilitation of adults with cancer diagnosis.
- Primary research is included if it presents an original definition that cannot be traced back to any other seminal work or review.

#### Exclusion criteria:

- Definitions that were presented in a language other than English.
- Documents discussing the rehabilitation of children with cancer or transition to adult services.

While these criteria were broad, this was necessary to encompass all available cancer rehabilitation definitions, which can influence healthcare professionals' and people's perceptions. After reading the available full-texts, 22 papers and textbooks were excluded as the cancer rehabilitation definition they contained could be traced back to other documents. Seventeen cancer rehabilitation definitions were included in this scoping review. The results of the literature search and selection process can be seen in Figure 1.

Figure 1 Flowchart presenting the definition selection process



#### Framework stage 4: Charting the data

In literature reviews it is good practice to chart the included papers to make the review process transparent (Peters et al. 2015). In this scoping review, the name of the authors, title of the documents, type of evidence, year of publication, country of origin, and the definitions were extracted to a chart, presented in Appendix 1.

#### Framework stage 5: Collating, summarizing and reporting the results

After selecting documents to include, it is good practice in scoping review to analyse and summarize the results. Depending on the data gathered, descriptive statistics or qualitative thematic analysis can be used (Levac et al. 2010). To analyse the definitions in this review, a simple thematic framework was used. Similarities and differences between cancer



rehabilitation definitions were compared, and common themes were developed. In this section, the results of the scoping review are presented.

The selected cancer rehabilitation definitions have been published in a wide range of different documents, namely: seminal works, reviews, textbooks, reports, position statements and congress papers. Thirteen definitions were developed and published in the United States (US), supporting that the concept of cancer rehabilitation has its origins in the US (DeLisa 2001). Two definitions originate from the United Kingdom (UK) one from Sweden, and one was a Nordic collaboration. Publication years range from 1974 to 2017. The first definition of cancer rehabilitation comes from Dietz (1974), a medical professional who specialised in rehabilitation in the US. Dietz is considered one of the founders of cancer rehabilitation along with Gunn and Rusk (Watson 1992). The latest cancer rehabilitation definition comes from Sweden and was published first in 2017 in a cancer rehabilitation report (Eckerdal 2017).

As the range of publication years and the number of documents (n=17) included in this review show, cancer rehabilitation has been of interest to healthcare professionals for many decades. However, there is not one universally accepted definition of cancer rehabilitation. While there are similar themes between definitions, differences can be identified in all of them. A common theme among definitions is the holistic nature of cancer rehabilitation. Even the earliest definitions (Dietz 1974) refers to not only physical rehabilitation of the person with cancer, but supporting their psychological, emotional, vocational, and financial or economic stability. Eight definitions mention these domains of health and wellbeing. Three documents define cancer rehabilitation as a service that aims to maintain (Veach et al. 2002) or improve quality of life (Wells and MacBride 2006, Cheville et al. 2007). Wells and MacBride (2006) developed their own rehabilitation definition based on Calman's (1984) quality of life concept. Calman (1984) defined quality of life as a gap between people's expectations and reality. Wells and MacBride (2006) proposed that rehabilitation should aim to bridge this gap.

Other definitions mention restoration to normal, optimal or maximum function (Gunn 1984, Mayer and O'Connor 1989, Watson 1990). However, what the authors understand by function (physical, psychosocial, or vocational) is not clearly specified. Watson's (1990) used the words "function" and "health problems" (p. 4.) rather than detailing the different health domains, because she aimed to make a universal cancer rehabilitation definition.

According to Watson (1990), referring to the consequences of cancer as health problems reflects inclusivity, because health problems could be minor and major. However, the interpretation of Watson's (1990) definition can depend on the reader's understanding of health. For some people health might not include psychological, spiritual, or vocational domains. The written context from which definitions were taken must be considered to clarify what function means for the different authors. For example, Gunn's (1984) definition did not describe function in a holistic way, although he discussed physical, psychological, spiritual, sexual, and vocational rehabilitation. Gunn (1984) stated that cancer rehabilitation should be dynamic depending on the needs of people affected by cancer.

There might be a need for a more specific definition, particularly because when quoting definitions, researchers or healthcare professionals may not always consider looking at the written context in which a definition was derived. For example, in her review of home rehabilitation services Blesch (1996) praises Mayer and O'Connor's (1989) definition for being the first to encompass all aspects of health and wellbeing, not just the physical domain, by saying "achieve optimal functioning" (p. 433.). However, if the reader goes beyond a simple, one sentence definition and examines whole seminal works, Mayer and O'Connor (1989) were not the first to include all aspects of health. Indeed, while Dietz (1974) starts his definition by comparing rehabilitation and readaptation, he goes beyond that, also stating the importance of psychological, emotional, and vocational rehabilitation. As Watson (1990) mentions, the terminology used in defining cancer rehabilitation must reflect the real intent of rehabilitative care to advance services and to address people's needs. Therefore, it is necessary to have a comprehensive definition, which encompasses the true meaning of rehabilitation and the wide range of health conditions and wellbeing states that can be managed by the services.

As mentioned above, the terminology used in definitions has an important role. Another common theme between definitions is the terminology used to indicate the person's and the healthcare professionals' role in cancer rehabilitation. Wells and MacBride (2006) criticised Gunn's (1984) definition for not placing the individual affected by cancer in the centre of rehabilitative care. A closer look at the words used in Gunn's (1984) definition reveals that it refers to rehabilitation as "the restoration of a patient" (p. 3.). Gunn's (1984) definition implies that healthcare professionals "restore" the individual into optimal functioning. This could send the message that people affected by cancer are the subjects of cancer rehabilitation, rather than the owners of their own health and wellbeing. Indeed,

Fried (1975) states: “We try to restore the patient as much as we can” (p. 277.). This suggests the person affected by cancer is not perceived as equal in the patient-professional relationship. This could indicate that historically there was a paternalistic medical model. The patients do as they are told.

However, not every definition from the 1970’s and the 1980’s implies that the individual affected by cancer is a passive recipient of healthcare professionals’ efforts to restore them. Indeed, Cromes (1978) defines rehabilitation as “helping the patient to help himself or herself” (p. 230.). This definition implies that people with cancer are responsible for their own health, the professional only has an assistive, almost teaching role towards the patient. Similar words, for example, “enable”, “promote health”, or “are assisted to achieve” can be identified in other definitions (McKenna et al. 1995, Mayer and O’Connor 1989, Watson 1990). This change in word use and the previously mentioned application of holistic needs coincides with the emergence of the biopsychosocial model (Engel 1977) and the need for a new medical model (Gordon 1981). While advances have been made over the years in terms of considering individuals with cancer as a ‘whole’, and involving them in their own healthcare, some more recent definitions still refer to cancer rehabilitation as “the treatment of symptoms and functional impairments” (p. 84.) (Gamble et al. 2011) or “diagnose and treat patients’ physical, psychological and cognitive impairments” (p. 3636.) (Silver et al. 2015). Thus, there is a sense in which healthcare interventions are perceived as being done to people. Indeed, these definitions indicate that people are perceived as passive in their recovery, which might result in misunderstanding cancer rehabilitation, and the inappropriate use of services.

Two other themes can also be identified in the selected definitions: the inclusion of family and carers in rehabilitation, and the time of rehabilitation. However, these themes are only mentioned in a few definitions. Indeed, family is only mentioned in two documents (Veach et al. 2002, Eckerdal 2017). However, families can be just as much affected by the cancer diagnosis as the individuals with cancer, especially if the vocational and economic functioning is considered as a domain of social need. If the individuals with cancer are working family members, being on sick leave and having reduced earnings can affect everyone in the household. Moreover, sometimes partners will give up work to take care of loved ones with cancer, which will result in reorganisation within the family. Therefore, cancer rehabilitation definitions need to include the family, as interventions should aim to support partners and children of people affected by cancer. As such, Veach et al. (2002)

defines rehabilitation as “the process by which patients and families are helped to recover their functional status” (p. 118.). Moreover, Eckerdal (2017) states that the “related support” or “next of kin” (Garmy and Jakobsson 2018) of the individual also needs help and support to lead a full life.

The timing of rehabilitation, particularly when it should commence has been a question of healthcare professionals since the concept of cancer rehabilitation emerged. Historically, it was considered that rehabilitative efforts should only start after treatments ended (Dietz 1974). However, Dietz (1974) suggested that rehabilitation should focus on prevention as much as on restoration and palliation. He states that rehabilitation should start as soon as there is a potential for impairment. Moreover, Dietz (1974) created a rehabilitation classification that breaks care into four stages depending on the times of need. Dietz (1974) divides cancer rehabilitation into preventative, restorative, supportive and palliative. To this date these stages are often cited in guidelines and reports (see for example, Welsh Assembly Government 2010). His staging is particularly important in the current healthcare climate where the importance of prevention, and promoting supportive therapies (physical therapy, counselling, peer support) from the time of diagnosis, frequently referred to as prehabilitation, is gaining wide recognition. However, until recently, no other definition mentioned the timing of rehabilitation in the cancer pathway. The Nordic Cancer Union (2004) refers to cancer rehabilitation as a specific period when the consequences of cancer are “prevented and reduced” (p. 4.). Gamble et al. (2011) suggest that rehabilitation should be applied to “many phases” of the cancer pathway (p. 62), while Silver et al. (2015) state that it should be provided throughout the “oncology care continuum” (p. 3636.).

In summary, there are numerous different definitions available for cancer rehabilitation. However, there is no universally agreed definition on which to draw. There are common themes between definitions, namely: looking at needs as holistic and not just the physical domain in isolation; the language used can indicate the role of the person affected by cancer in their own rehabilitation (subject of rehabilitation or having the control); time of rehabilitation; and the involvement of family. However, some definitions only contain one or two of these themes. This can result in professionals using definitions with missing or inadequate information, which might make it harder to compare rehabilitation programmes developed in different settings. Moreover, it can influence people’s perception of rehabilitation, which might influence their willingness to use services.

However, limitations of this literature review must be addressed. These findings are indicative of the use of cancer rehabilitation definitions, but not definitive. The literature search was limited to definitions available in English language. Therefore, it is possible that cancer rehabilitation definitions were missed which are used in other countries where English is not commonly spoken. Moreover, the literature search and selection process was conducted by one person, the author of this PhD study, thus could be a potential source of bias. To conduct a scoping review, consultations with experts can be conducted, although this step is optional (Arksey and O'Malley 2005). The findings of this review were discussed with the supervisory team, who have experience in cancer and supportive care, although no other experts had input into the review, which could lead to potential bias.

## 2.2 Cancer rehabilitation definition used in this PhD study

To further investigate what works in cancer rehabilitation, for whom, in what circumstances and how, it is important to define what the author understand as cancer rehabilitation. As the findings of this scoping review show, there is no universally accepted cancer rehabilitation definition, and in many definitions one or two of the above presented themes are absent. Therefore, for the purposes of this PhD study I propose a definition which contains all four main themes discussed above:

**Cancer rehabilitation is a complex set of interventions aiming to enable people affected by cancer and their families to achieve maximal physical, psychological, emotional, social, and economic functioning within the limits of the disease, from diagnosis until the end of life.**

## 2.3 Conclusion

The aim of this scoping review was to investigate how cancer rehabilitation was defined in the literature. The results show that there is no globally accepted definition for cancer rehabilitation. There are common themes between different definitions, although these themes are not always present in every iteration. This can result in people having different understanding of cancer rehabilitation, which can influence service provision and attendance. However, not only the definition of cancer rehabilitation can influence how services work. Several other barriers exist, which could influence how cancer rehabilitation

services are provided. The aim of the next chapter is to review the literature on barriers and facilitators of cancer rehabilitation.

## Chapter 3: Barriers and facilitators of cancer rehabilitation – literature reviews from two perspectives

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In this chapter two literature reviews are presented from the perspectives of people affected by cancer and healthcare professionals to critically review the literature on the barriers and facilitators of cancer rehabilitation. As people treated for cancer in Wales can be left with unmet physical and emotional needs (Welsh Government 2014b,2017), it is important to identify and examine factors which may contribute to insufficient cancer rehabilitation and support. Examining the published empirical research and review literature highlights potential barriers and facilitators to provide a theoretical basis for this realist evaluation study. In this chapter, firstly, the rationale for this literature review is clarified, then the literature review designs are introduced. Then an overview of qualitative research reviews is presented from the perspective of people affected by cancer. Following the overview of qualitative research reviews, a qualitative synthesis of the literature from the healthcare professionals' perspective is presented.

### 3.1 Rationale for the literature review

The 'Improving Supportive and Palliative care for Adults with Cancer' guidance (NICE (2004) identified that the barriers to comprehensive cancer rehabilitation in the UK include: professionals' lack of knowledge and experience in recognising rehabilitation needs; insufficient workforce capacity of allied health professionals (AHPs); lack of training for professionals and issues with prioritising rehabilitation, causing delays in access to facilities and equipment. However, this now rather dated guidance is not based on empirical evidence. Furthermore, the NICE (2004) guidance advisory board had just one Welsh member, which may render the cancer rehabilitation barriers identified less generalisable to the Welsh context. Moreover, the Welsh healthcare system has changed since the guidance was published and thus, these barriers may not be representative of how services are presently provided. For example, in 2009 NHS Wales went through major change. Seven University Health Boards were created to oversee healthcare services, replacing 22 local health boards and seven NHS Trusts (HFMA 2018). In addition, the NHS workforce increased from 72,698 to 79,054 people since 2009, so as the number of people accessing the health services for treatments (Welsh Government 2019).

The National Cancer Action Team (NCAT) published the 'Supporting and Improving Commissioning of Cancer Rehabilitation Services' guidelines in 2009 to help healthcare professionals in meeting people's rehabilitation needs. Like the NICE (2004) guidance, these guidelines mention professionals' lack of cancer rehabilitation knowledge and AHP staff shortages as barriers. In addition, NCAT added insufficient funding, lack of evidence, process monitoring and model of service delivery as further difficulties in providing cancer rehabilitation. However, the NCAT guidelines lack generalisability, due to publication date, focus on services in London, and opacity with regard to how these barriers were identified. Therefore, the aim of the literature reviews presented in this chapter was to identify and critically explore the recent empirical and review literature on the barriers to and facilitators of cancer rehabilitation from the perspective of healthcare professionals and people affected by cancer.

Exploring the perspectives of people affected by cancer is crucial, as both the NICE guidance and the NCAT guidelines lack the perspectives of people affected by cancer and rely on the authors' perceptions of people's rehabilitation needs. Therefore, looking at the empirical literature only from healthcare professionals' perspective would have resulted in missing important barriers and facilitators of cancer rehabilitation. In addition, NHS Wales strives towards co-production, meaning that shared decisions should be made by the public and healthcare professionals regarding healthcare service use and development. Arguably, including literature from people's perspective to identify barriers and facilitators can support co-production.

## 3.2 Literature review designs

As a first step in conducting a literature review, the type of research papers most appropriate for the aims of reviewing the literature was chosen. Qualitative interviews can provide rich descriptions of the topic under investigation, and often consider the context of the research (Braun 2013). This is particularly important when looking at international literature, in which the healthcare systems might differ from the NHS. However, looking at the wider literature can help identify similarities and difference between cancer rehabilitation in the UK and other countries, and it can provide an opportunity to learn what works in other cancer rehabilitation models. Therefore, the two literature reviews focused on qualitative research investigating the barriers and facilitators of cancer



rehabilitation from the perspectives of people affected by cancer and healthcare professionals.

To achieve a manageable yet wide-ranging investigation, two different review designs were used. From the perspective of people affected by cancer an overview of qualitative research reviews was conducted (Hunt et al. 2018). The methodological approach of overview of reviews have been developed as the number of systematic reviews significantly increased in recent years (Smith et al. 2011). Overview of reviews is gaining recognition as it can quickly summarise and compare the findings of systematic literature reviews, providing a useful and prompt tool for decision makers wanting to access the best evidence possible (Smith et al. 2011). Overview of reviews was chosen for the literature review from the perspectives of people affected by cancer, as research investigating people's experiences with cancer rehabilitation interventions steadily increased over the years. Numerous qualitative studies investigating cancer rehabilitation and its barriers and facilitators can be found. Moreover, in recent years the publication of qualitative syntheses based on the empirical cancer rehabilitation literature increased. Good quality systematic reviews of the qualitative literature can provide rich information on the barriers and facilitators to service implementation and provision (May et al. 2014). Therefore, qualitative literature reviews were considered a sufficient alternative for original qualitative studies. To summarise the findings of the included qualitative syntheses, Holm et al.'s (2020) method was used. This overview of reviews method involves coding the findings of included research syntheses and organising codes into themes and subthemes. These themes and subthemes can highlight similarities and difference between the included qualitative research reviews (Holm et al. 2020).

From healthcare professionals' perspective fewer qualitative research papers investigating cancer rehabilitation have been published. Therefore, to review the literature from healthcare professionals' perspective, qualitative synthesis with original research papers were conducted based on the method of Thomas and Harden (2008). Thomas and Harden's (2008) method was initially developed for systematic reviews, but have been used in a wide range of literature reviews since, for example integrative reviews (Browall et al. 2018). Thomas and Harden's (2008) method is unique as it uses thematic synthesis to review qualitative papers. Thematic synthesis is undertaken in three stages: coding, developing descriptive themes, and generating analytical themes. These stages were followed for the review of qualitative research from healthcare professionals' perspective.

The search strategies, selection processes and findings of the overview of reviews and the qualitative synthesis are presented separately. Firstly, the overview of reviews is introduced.

### 3.3 Overview of qualitative research reviews from the perspective of people affected by cancer

As mentioned earlier, people affected by cancer in Wales do not always receive practical or emotional support when they need it (Welsh Government 2014b,2017). Some barriers and facilitators of cancer rehabilitation have been discussed in guidance available in the UK. However, these examine the barriers only from healthcare professionals' perspective. Therefore, this overview of reviews aims to explore the literature from the perspective of people affected by cancer. This literature review seeks to answer the following research questions:

1. What are the barriers to people affected by cancer accessing cancer rehabilitation services?
2. What are the facilitators of people affected by cancer accessing cancer rehabilitation?

#### 3.3.1 Search strategy for the overview of reviews

The following electronic databases were searched for peer reviewed reviews of the qualitative literature on the barriers and facilitators of cancer rehabilitation: MEDLINE, CINAHL Plus, and Web of Science. To make the literature review more specific to this thesis, a search term focusing around one of the main interventions provided by the Willow Therapy Team was added, namely: exercise. No time limit was set for the literature searches to enable comparison of different barriers over the years. Reference list of relevant qualitative review papers were hand searched to identify potentially useful papers not identified by the electronic searches and which could be included in this overview of reviews. Moreover, Google, Google Scholar, and University Library was also searched to map the literature. The search terms used to find qualitative review papers from the perspectives of people affected by cancer are presented in Table 5.

Table 5 Terms and their combination used in electronic database searching to find review papers from the perspectives of people affected by cancer

<b>Search terms used for identifying barriers and facilitators of cancer rehabilitation from the perspectives of people affected by cancer</b>
Exercise AND cancer AND qualitative AND barrier
Rehabilitation AND cancer AND barrier AND review
Exercise AND cancer AND barrier AND review
Exercise AND cancer AND qualitative AND barrier AND review

### 3.3.2 Inclusion and exclusion criteria for the overview of qualitative research reviews

Inclusion and exclusion criteria to screen the results of the electronic database searches were chosen to reflect the interventions provided by the Willow and Fern Therapy Teams. The two services focus on interventions provided by AHPs, namely: exercise groups, physiotherapy, speech and language therapy, input from OTs and dietitians. These interventions have been found to help maintaining functional mobility, build fitness and improve mental health (Hunter et al. 2017a,b), which all fit into the concept of cancer rehabilitation discussed in chapter 2. Mixed method literature reviews were included in this overview of qualitative reviews if they contained qualitative interview or focus group research investigating the perspectives of people affected by cancer.

Inclusion criteria:

- Qualitative synthesis, metasynthesis, systematic, integrative, or scoping reviews exploring the barriers and facilitators of cancer rehabilitation from the perspectives of people affected by cancer.

Exclusion criteria:

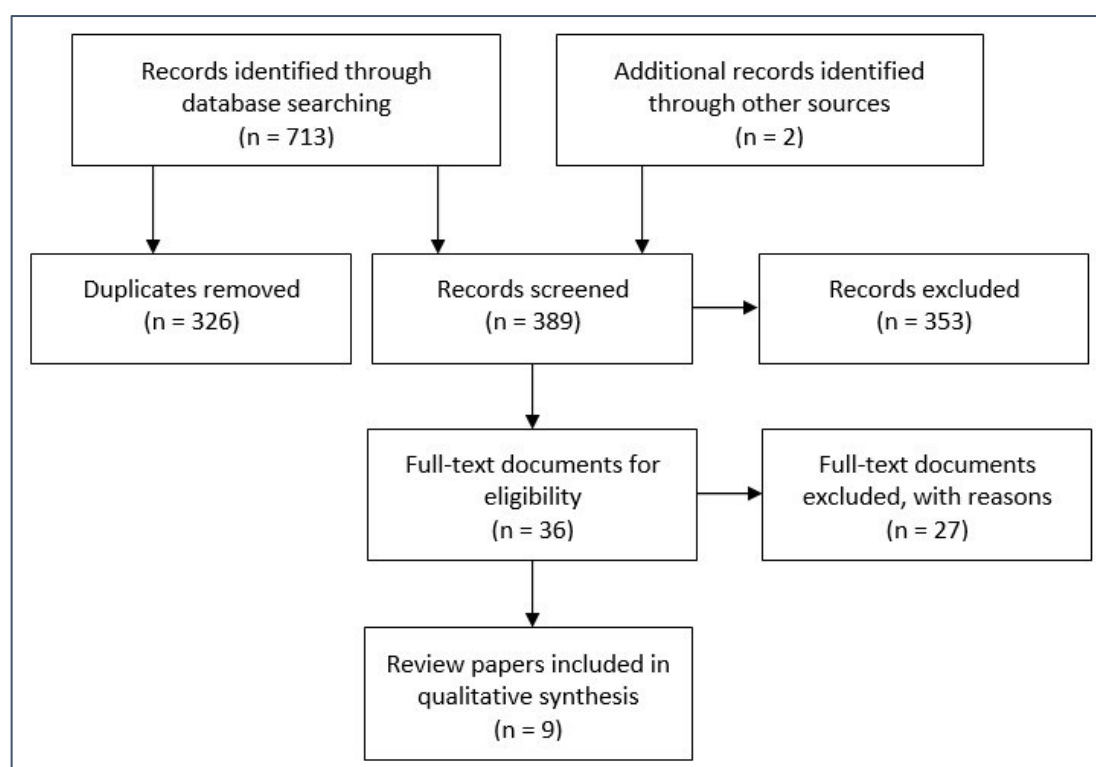
- Literature exploring the experiences of children or adolescents affected by cancer.
- Literature that does not explore the barriers and facilitators of cancer rehabilitation interventions, exercise, dietary advice, speech and language therapy or palliative rehabilitation of people affected by cancer.

- Literature mainly focusing on the effectiveness of cancer rehabilitation interventions and not considering barriers and facilitators of clinical implementation and use. For example: quantitative systematic reviews, metanalysis
- Literature solely focusing on the barriers and facilitators of cancer screening and prevention.
- Literature only involving surgical and pharmacological rehabilitation of people affected by cancer.
- Literature only focusing on surgical prehabilitation, but not on cancer rehabilitation as a whole, encompassing the cancer pathway from diagnosis till the end of life.
- Literature solely focusing on 'Return to work' interventions.
- Literature only focusing on web-based or telehealth interventions.
- Literature reviews written as conceptual overviews of cancer rehabilitation and not synthesising empirical literature from the perspectives of people affected by cancer.

### 3.3.3 Review paper selection process

The database searches generated 713 hits. Two additional review papers were found through Google, Google Scholar, University Library search. After the removal of 326 duplicates, the titles and abstracts of 389 papers were screened against the inclusion and exclusion criteria. A further 353 papers were excluded leaving 36 papers for full-text review. Out of these, 27 did not meet the inclusion criteria and were therefore excluded. The flowchart of review selection can be seen in Figure 2 below.

Figure 2 Flowchart presenting the review paper selection process



Extracting data from the included papers is a good practice in literature reviews. For this overview of qualitative research reviews the following data was extracted from the included qualitative review papers: authors, year, location, sample, method, risk of bias, and themes. The data extraction sheet is presented in Appendix 2.

### 3.3.4 Characteristics of the included qualitative review papers

Review articles synthesising qualitative research from the perspectives of people affected by cancer were published between 2015 and 2020. The reviews were conducted in a range of countries: Australia (n=1); Canada (n=1); Denmark (n=1); Sweden (n=1); UK (n=3); USA (n=1). There was one collaboration between Australia and the UK. All review papers included were published in peer-reviewed journals. No reports or grey literature were included in this overview of qualitative research reviews from the perspectives of people affected by cancer.

The review methods were mainly systematic (n=7), although one integrative and one scoping review were also included. Out of the nine papers, three were registered in the International Prospective Register of Systematic Reviews (PROSPERO). Based on the literature included in these reviews, four papers were mixed methods systematic reviews,

and five were qualitative syntheses. Six studies used the qualitative synthesis method of Thomas and Harden (2008). One paper did not specify the method of qualitative synthesis (Michael et al. 2020), and another used the framework of Sandelowski et al. (2007) (Midtgaard et al. 2015). The one scoping review (Yannitsos et al. 2020) followed the steps established by Arksey and O'Malley's (2005) framework.

The interventions investigated in the included reviews were exercise-based rehabilitation ( $n=1$ ), exercise ( $n=7$ ) and lifestyle modification during and after treatment ( $n=1$ ). Cancer sites investigated in these reviews were breast ( $n=4$ ), lung ( $n=1$ ), prostate ( $n=2$ ) and mixed ( $n=2$ ).

### 3.3.5 Critical appraisal of review papers

To explore the quality of the included literature the Critical Appraisal Skills Programme (CASP) tool for systematic reviews was used (Critical Appraisal Skills Programme 2019b). Critical appraisal of the literature is necessary to support the credibility of the findings (Thomas and Harden 2008). The included review papers from the perspectives of people affected by cancer had generally good quality based on the CASP tool. CASP scores ranged from 7 to 9. The reasons for the scores are presented in Appendix 30. The most common issue of concern with the systematic reviews and the included integrative review was the scope of inclusion criteria. In all reviews, papers published in English language were included, limiting the findings. In two reviews, the critical appraisal methods were clearly described, although the biases were not detailed, leaving the reader wondering what the issues were with the included papers (Browall et al. 2018, Clifford et al. 2018).

The scoping review (Yannitsos et al. 2020), included in this literature review was evaluated with the PRISMA checklist (Tricco et al. 2018). Yannitsos et al.'s (2020) paper was generally of good quality. However, issues were noted including: no apparent registration of the review or review protocol; no detailed description of the search term combinations or limits used; funding sources were not explicitly disclosed; and lack of critical appraisal. Nevertheless, the latter is not necessarily required in scoping reviews.

### 3.3.6 What are the barriers to people affected by cancer accessing cancer rehabilitation services?

Findings from the different qualitative synthesis papers were summarised by following the methods described by Holm et al. (2020). First, the included review papers were read in full by using Adobe Acrobat Reader. While reading the full-text, initial notes and codes were made about the results section of the qualitative syntheses. Then, the full text papers were imported into NVivo version 12, to finalise codes, and organise findings into themes. While conducting the overview of qualitative research reviews, three main themes were identified as barriers from the perspectives of people affected by cancer: challenges unique to the person affected by cancer, insufficient information provision regarding cancer rehabilitation and exercise, and accessibility of services.

#### 3.3.6.1 *Challenges unique to the person affected by cancer*

The challenges unique to the person affected by cancer covers issues that can act as barriers to cancer rehabilitation if present in the individual's life. Potential challenges include ageing with comorbidities, cancer symptoms, treatment related effects, individual's need to prioritise work and family, overprotective family, and individual's motivation to attend cancer rehabilitation and exercise.

Several reviews highlighted that people affected by cancer found old age and other comorbidities as barriers to cancer rehabilitation and exercise (Browall et al. 2018, Granger et al. 2017, Lavalée et al. 2019, Yannitsos et al. 2020). Older people were often not motivated to participate in rehabilitation or exercise. Primarily this was because they did not think they could benefit from it or were fearful it would negatively impact on their health and functional ability, which were often already compromised by a sequela of problems from cancer, its treatments and pre-existing conditions. Indeed, older people are more likely to live with comorbidities which can make exercising or participating in other activities difficult (Williams et al. 2016).

Cancer symptoms and treatment related long-term and late effects, most notably cancer related fatigue, sometimes precluded individuals' engagement in rehabilitation interventions which, ironically, may aid the management of these problems (Browall et al. 2018, Granger et al. 2017, Lavalée et al. 2019, Yannitsos et al. 2020). Other treatment effects hindering individuals' engagement with cancer rehabilitation and exercise were site

specific. For instance, people affected by breast cancer often experienced altered body image both during and post treatment as a consequence of surgery, hair loss or weight gain (Browall et al. 2018, Lavalée et al. 2019, Livsey and Lewis 2018). These body changes held some women back from carrying on with usual physical activities or joining new exercise groups (Lavalée et al. 2019).

Other unique challenges were that people often had to prioritise family and work over cancer rehabilitation or engaging in physical exercise (Browall et al. 2018, Clifford et al. 2018, Fox et al. 2019, Granger et al. 2017, Lavalée et al. 2019). The demanding nature of cancer treatments necessitates priority setting. For many joining exercise groups or participating in rehabilitation was often a low priority, particularly if it required lengthy travelling. Individuals often felt guilty taking time away from family or taking time off work was not an option. Therefore, they had to forgo participating in interventions that may have improved their quality of life (Yannitsos et al. 2020).

In addition, it has been reported in the reviews, that family can negatively influence motivation to exercise or participate in rehabilitative interventions (Browall et al. 2018, Granger et al. 2017, Lavalée et al. 2019). Family and friends often try to protect their loved ones from harm, or what they perceive as harm. Some even facilitate a “rest is best” mentality (Browall et al. 2018). The support network often acted out of fear of physical harm to people affected by cancer and that is why they advised against being active or changing lifestyles (Lavalée et al. 2019).

The last issue that could be a challenge unique to the individual was motivation to attend cancer rehabilitation and exercise. People’s past experiences and relationships with physical exercise often influenced their behaviour towards taking part in exercise-based rehabilitation (Browall et al. 2018, Clifford et al. 2018, Fox et al. 2019, Lavalée et al. 2019, Granger et al. 2017). People who pre diagnosis did not identify as a “sporty type” or found lack of enjoyment in certain physical activities, were less likely to engage in exercise-based cancer rehabilitation (Browall et al. 2018, Clifford et al. 2018). However, people who had been physically active before diagnosis were more likely to engage in exercise and exercise-based rehabilitation post diagnosis (Granger et al. 2017). In addition, uncertainty and depression due to diagnosis and treatments often resulted in people not being motivated to exercise or join rehabilitation programmes (Baker et al. 2015, Browall et al. 2018, Granger et al. 2016, Granger et al. 2017, Lavalée et al. 2019). Furthermore, exercise or



rehabilitation groups were often seen as reminders of cancer, particularly when provided in hospital settings.

#### *3.3.6.2 Insufficient information provision*

Some reviews highlighted that people affected by cancer often did not receive sufficient information regarding their diagnosis and what they can and cannot do during treatment (Browall et al. 2018, Clifford et al. 2018, Fox et al. 2019, Granger et al. 2017). This often resulted in uncertainty and anxiety which could lead to people not engaging in rehabilitation or lifestyle change. Insufficient information often drove people towards self-seeking information if they were motivated to keep fit. However, the absence of professional help often resulted in a lingering fear of not doing the right thing.

Even when people received information from healthcare professionals, it was often conflicting. This resulted in a fear of engaging in rehabilitation and exercise (Browall et al. 2018, Granger et al. 2017, Lavalleyé et al. 2019, Yannitsos et al. 2020). Different professionals providing different and conflicting information on exercise and lifestyle change made some people question the professionals' knowledge (Browall et al. 2018). Others became frustrated and did not dare commence new physical activities or resume with old hobbies (Granger et al. 2017).

#### *3.3.6.3 Accessibility of cancer rehabilitation services*

Some reviews showed that accessibility of cancer rehabilitation services was problematical when people affected by cancer had to travel long distances to participate (Granger et al. 2017, Yannitsos et al. 2020). Furthermore, this often incurred extra out of pocket expenses and loss of time that could have been spent in other meaningful ways. Adequate transportation was an issue for some people affected by cancer because some treatments could render them medically unsuitable to drive (Granger et al. 2017).

#### **3.3.7 What are the facilitators of people affected by cancer accessing cancer rehabilitation?**

Three main themes were identified that facilitated people to access and attend cancer rehabilitation. The three themes were: raising awareness, individualised tailored care, and understanding environment.

#### *3.3.7.1 Raising awareness*

Providing information on the benefits of cancer rehabilitation and exercise can facilitate uptake and adherence (Browall et al. 2018, Granger et al. 2017). Knowledgeable clinicians are trusted sources of information, and people affected by cancer valued healthcare professionals' opinions on cancer rehabilitation and exercise (Yannitsos et al. 2020). Physicians and nurses were found to be healthcare professionals that people relied on the most (Granger et al. 2017). Therefore, these professionals should aim to raise awareness of cancer rehabilitation. However, raising awareness of cancer rehabilitation services and the role of exercise should be every healthcare professionals' responsibility and information provided should be consistent between different disciplines (Fox et al. 2019). This is particularly important, for as seen earlier in this chapter, conflicting information from healthcare professionals can lead to people avoiding cancer rehabilitation and exercise.

#### *3.3.7.2 Individualised, tailored care*

To meet people's rehabilitation needs, cancer rehabilitation services need to be tailored to people's needs and provide individualised input. Choice is important, as having options can enable people to find a suitable programme that can help them to achieve their goals, whether it is getting fit after cancer treatments or improving quality of life (Fox et al. 2019). For example, having a choice in how rehabilitation programmes are delivered can facilitate adherence. Some people enjoyed the flexibility and routine of individual home-based exercise (Browall et al. 2018, Granger et al. 2017) while others preferred group sessions (Yannitsos et al. 2020). Ultimately, programmes need to be convenient, to attract more people (Granger et al. 2017).

In addition, setting achievable goals tailored for people affected by cancer can help improve individuals' self-efficacy, which, if successful, could lead to long term adherence to interventions and exercising (Lavalée et al. 2019, Michael et al. 2020). Moreover, people affected by cancer appreciate monitoring and feedback from healthcare professionals, which makes improvements tangible and real (Fox et al. 2019, Granger et al. 2017).

#### *3.3.7.3 Understanding environment*

Understanding environment entails three subthemes: "spontaneous" peer support, supportive relationships with healthcare professionals, and backing from the family. As

mentioned in the previous section, some people enjoyed attending rehabilitation programmes delivered in group format. One of the reasons for preferring group sessions was the “spontaneous” peer support (Fox et al. 2019) and “informal counselling” provided by other people affected by cancer and healthcare professionals (Midtgaard et al. 2015). “Spontaneous” peer support appeals to people in exercise groups, as they can meet peers, but not feel like they are in an organised support group session, which can often act as a deterrent for people who would like to forget about their cancer experience. Talking about cancer is optional in the group (Lavalée et al. 2019). In addition, exercise and rehabilitation groups often acted as distractions (Lavalée et al. 2019, Midtgaard et al. 2015), taking focus away from cancer and the fear that came with the diagnosis (Livsey and Lewis 2018).

Another important element of effective rehabilitation or exercise programmes is the nature of the relationship between healthcare professionals and the participants. Supportive, open relationships with healthcare professionals facilitate attendance and adherence (Browall et al. 2018, Granger et al. 2017, Lavalée et al. 2019, Livsey and Lewis 2018). In addition, healthcare professionals’ knowledge increases trust in the programme. Supportive relationships with healthcare professionals and the “spontaneous” peer support can create an understanding environment, which is important for people affected by cancer, particularly, if they have altered body image issues post treatments (Lavalée et al. 2019, Livsey and Lewis 2018, Mitgaard et al. 2015).

In addition, some reviews found that family and social support can be a facilitator of cancer rehabilitation and exercise attendance (Granger et al. 2017, Yannitsos et al. 2020). The individual’s family and social support can be of help in two ways. Family members were more likely to remember information given by physicians or the multidisciplinary team than the person affected by cancer, which can aid sufficient information provision (Granger et al. 2017). Moreover, family members and friends provided motivation and practical support for people affected by cancer to do exercises or make dietary changes (Yannitsos et al. 2020).

### 3.3.8 Summary of the overview of reviews

This overview of reviews examining the cancer rehabilitation literature from the perspectives of people affected by cancer shows that there are numerous barriers to cancer rehabilitation. Some challenges are unique to the individual with cancer, such as the impact

of age and comorbidities, or the burden of late and long-term effects of cancer treatments. However, other barriers are related to cancer rehabilitation service provision, and healthcare professionals' knowledge on cancer rehabilitation. However, to contrast the barriers various facilitators can help people engage in cancer rehabilitation and exercise. Raising awareness of cancer rehabilitation and exercise, individualised, tailored care, and a supportive environment can help people access and benefit from cancer rehabilitation.

### 3.4 Qualitative synthesis of the cancer rehabilitation literature from the healthcare professionals' perspective

This qualitative synthesis aims to review original, qualitative research literature investigating healthcare professionals' perspectives on cancer rehabilitation. This qualitative synthesis aims to answer the following questions:

1. What are the barriers to cancer rehabilitation service provision from healthcare professionals' perspectives?
2. What are the facilitators of cancer rehabilitation service provision from healthcare professionals' perspectives?

#### 3.4.1 Search strategy for the qualitative synthesis

To find qualitative research studies the electronic databases of MEDLINE, CINAHL Plus, and Web of Sciences were searched. Terms, such as rehabilitation and exercise were used to retrieve original research investigating the barriers to cancer rehabilitation. These searches mainly provided results where the interviewed professionals were physicians, physiotherapists, occupational therapists, or exercise trainers. To include a wider range of healthcare professionals, who are also involved in cancer rehabilitation, search terms, such as 'professional\*', 'clinician\*', 'speech and language therap\*' and 'dietitian' were added. Boolean operators and wildcards (therap\*) were used to help restrict or expand the literature search. For transparency and rigor, terms and their combinations used to search the electronic databases for healthcare professionals' experiences are presented in Table 6.

Table 6 Terms and their combinations used in electronic database searching to find qualitative research from healthcare professionals' perspectives

<b>Search terms used for identifying barriers and facilitators of cancer rehabilitation from the perspectives of healthcare professionals</b>
Rehabilitation AND cancer AND barrier AND qualitative AND (professional* OR clinician*)
Exercise AND cancer AND barrier AND qualitative AND (professional* OR clinician*)
Speech and language therap* AND cancer AND qualitative
Dietitian AND cancer AND qualitative

Google and Google Scholar searches were also conducted to find potentially relevant grey literature, such as reports, and research conducted by third sector organisations. Moreover, reference lists of relevant papers were hand searched to find potential qualitative studies investigating healthcare professionals' experiences.

### 3.4.2 Inclusion and exclusion criteria for the qualitative synthesis

Similar to the overview of qualitative research reviews, inclusion and exclusion criteria to screen the results of the electronic database searches were chosen to reflect the interventions provided by the Willow and Fern Therapy Teams. The two services focus on interventions provided by AHPs, namely: exercise groups, physiotherapy, speech and language therapy, input from OTs and dietitians.

Inclusion criteria:

- Peer-reviewed or grey literature reporting on qualitative individual interviews or focus groups with healthcare professionals that focus on the barriers and facilitators of cancer rehabilitation, exercise, dietary advice, speech and language therapy or palliative rehabilitation for people affected by cancer.

Exclusion criteria:

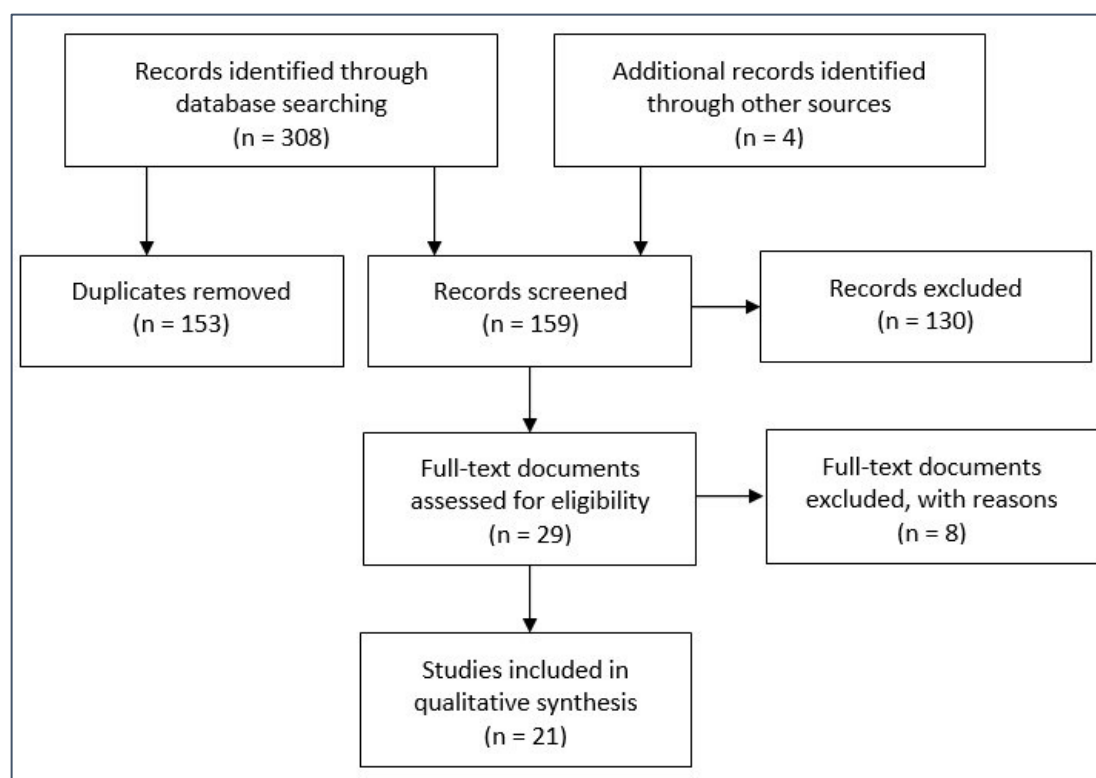
- Literature exploring the experiences of children or adolescents affected by cancer.
- Literature that does not explore the barriers and facilitators of cancer rehabilitation interventions, exercise, dietary advice, speech and language therapy or palliative rehabilitation of people affected by cancer.

- Literature mainly focusing on the effectiveness of cancer rehabilitation interventions and not considering barriers and facilitators of clinical implementation and use. For example: randomised control trials (RCTs).
- Literature solely focusing on the barriers and facilitators of cancer screening and prevention.
- Literature only involving surgical and pharmacological rehabilitation of people affected by cancer.
- Literature only focusing on surgical prehabilitation, but not on cancer rehabilitation as a whole, encompassing the cancer pathway from diagnosis till the end of life.
- Literature solely focusing on 'Return to work' interventions.
- Literature only focusing on web-based or telehealth interventions.

### 3.4.3 Qualitative study selection

Database searches resulted in 308 hits. From Google and Google Scholar searches, four additional research studies were found. After the removal of 153 duplicate articles, the titles and abstracts of 159 articles were screened against the inclusion and exclusion criteria. After the exclusion of 130 research papers, 29 full-text articles were checked for eligibility. After this process, 21 qualitative research studies on the barriers and facilitators of cancer rehabilitation from the perspective of healthcare professionals were included in this qualitative synthesis. No relevant papers were identified from handsearching reference lists. The flow chart of literature selection from healthcare professionals' perspectives is presented in Figure 3.

Figure 3 Flowchart presenting the selection process for papers from healthcare professionals' perspectives



Extracting data from the included qualitative studies is a good practice in literature reviews, as it aids transparency and rigour (Lockwood et al. 2020). For this qualitative synthesis the following data was extracted from the included qualitative research studies: authors, year, location, intervention, sample, method, and themes. The data extraction sheet is presented in Appendix 3.

#### 3.4.4 Characteristics of qualitative research studies

The 21 original qualitative research studies were published between 2008 and 2020. These studies were conducted in several different countries: Australia (n=3); Canada (n=5); Denmark (n=1); The Netherlands (n=1); Spain(n=1); Sweden (n=3); UK (n=5); and the USA (n=2). Regarding studies conducted in the UK, two studies were multicentre (Bourke et al. 2018, Kenyon et al. 2020), while one specifically focused on Cardiff, Wales (McCartney et al. 2011), one on Northern Ireland (Payne et al. 2018), and one on London (Transforming Cancer Services Team 2017b). Twenty papers were published in peer-reviewed journals and one qualitative research was conducted as part of a scoping report of services (Transforming Cancer Services Team 2017b). The report was included in this qualitative

synthesis, as it was exploring cancer rehabilitation within the UK and provided a more accurate, generalisable account to the barriers and facilitators of the services.

The methods of investigation were focus group in eight studies, individual interviews in nine and both in four studies. Within the 21 studies, two also included clinical observations (Beidas et al 2014, Handberg et al. 2018). The qualitative analytic method varied in the studies, with most papers using content analysis (n=6), or thematic analysis (n=5). The remaining studies reported phenomenological approaches, grounded theory, framework analysis, descriptive qualitative analysis, and data tabulation. For one study it could not be determined if the analytic method was content or thematic analysis, as the terms were used interchangeably (Granger et al. 2016).

The interventions, for which the barriers and facilitators were explored, were: exercise (n=2); exercise counselling (n=4); exercise programme implementation (n=2 in general, and n=1 implementation for a specific programme); rehabilitation/exercise guideline implementation (n=2); palliative rehabilitation (n=1); practical support (n=2); rehabilitation intervention (n=4 broad, including exercise and other); upper limb physiotherapy for people affected by breast cancer (n=1); weight management (n=2).

The healthcare professionals interviewed were mainly physicians and nurses, although AHPs were included in some studies. Two studies did not include any AHP interviews (Payne et al. 2018, Romero-Elías et al. 2020), while two studies did not specify the role of the AHPs (Shea et al. 2019, Transforming Cancer Services Team 2017b). The included AHPs were dietitians in one paper, physiotherapists in five, mammogram technicians in one and therapy radiographers in another study. In nine studies, besides physicians and nurses a mixture of AHPs was interviewed, for example OTs, social workers, kinesiologists, rehabilitation scientists. Twelve original qualitative research papers focused on the following cancer sites: brain (n=1), breast (n=5), colorectal (n=1), lung (n=2), and prostate (n=2). The remaining papers reported interviews with professionals from a mixture of cancer specialties (n=4), or the intervention was not specific to any cancer sites (n=6). Besides the healthcare professionals' perspectives, six papers included interviews with people affected by cancer.



### 3.4.5 Critical appraisal of qualitative studies

To explore the quality of the included literature the Critical Appraisal Skills Programme (CASP) tool for qualitative studies was used (Critical Appraisal Skills Programme 2019a). The original qualitative research papers from the perspective of healthcare professionals had moderate to good quality. The papers based on the CASP tool scored between 5 and 9. The most common issues with the included paper were the lack of reflection and exploration of the relationship between researchers and study participants. Exploring and disclosing relationships between researchers and participants is an important part of qualitative research because if the interviewer is known to interviewees, they might disclose different information than to a stranger or to a figure that they see as authority (Reventlow and Tulinius 2005).

The recruitment strategy or why certain professionals were picked for interviews were often not explicitly described. For focus groups in some articles the group dynamics between professionals were not indicated. However, this could influence the findings, particularly if there is a hierarchical dynamic within the group, for example lead nurse and nurse assistant (Robson 2016). Regarding analysis, it was rarely mentioned who performed transcription. Interviews in every paper were audio recorded and transcribed verbatim. However, transcription is an important phase in qualitative analysis, as researchers can familiarise themselves with the data, providing better insight into developing candidate themes (Riessman 1993). If transcription is delegated to an independent transcription service, transcripts need to be checked for accuracy, which was often not mentioned in the papers. Study limitations and measures to ensure rigour were not always stated, making the findings questionable. More details on the quality issues of included original qualitative research papers from healthcare professionals' perspectives can be found in Appendix 31.

### 3.4.6 What are the barriers to cancer rehabilitation service provision from healthcare professionals' perspectives?

To summarise the findings from different papers, Thomas and Harden's (2008) thematic synthesis method was used. The included papers were first read in Adobe Acrobat Reader DC, where notes were made, and important sections were highlighted. Then the papers were imported to NVivo version 12, where the text was re-read and coded. When all papers were read and coded in NVivo, nodes were collapsed into themes and subthemes. Two

main themes were identified as barriers to cancer rehabilitation: professionals' lack of knowledge and understanding of cancer rehabilitation, and service organisation and delivery.

#### *3.4.6.1 Healthcare professional's lack of knowledge*

As seen in the overview of reviews (section 3.3.6.2), people affected by cancer often receive insufficient or conflicting information about cancer rehabilitation and exercise. In some cases, conflicting information led to people questioning healthcare professionals' knowledge. From the perspective of healthcare professionals', lack of knowledge about cancer rehabilitation was reflected in their referrals to services, and confidence to provide information and support to people affected by cancer (Kenyon et al. 2020, McCartney et al. 2011, Neher et al. 2020, Olsson Moller et al. 2020, Shea et al. 2019). Professionals often did not know about available cancer rehabilitation services, which had an effect on their referrals (McCartney et al. 2011, Neher et al. 2020, Olsson Moller et al. 2020, Shea et al. 2019) and thus on the support people received. Healthcare professionals also had inadequate knowledge of behaviour change theories and techniques (Bourke et al. 2018, Dennet et al. 2020, Granger et al. 2016). This often held them back from providing information or led to fear of inability to motivate people affected by cancer (Bourke et al. 2018). This knowledge deficit partially stemmed from lack of detailed guidelines, and healthcare professionals' lack of formal education on cancer and cancer rehabilitation. However, gaining experience in their own practice, self-seeking training and information helped professionals increase their confidence and provide support to people affected by cancer (Kenyon et al. 2020).

Moreover, issues with knowledge on cancer rehabilitation did not just affect healthcare professionals working in clinical practice. Hospital management often had insufficient knowledge on cancer rehabilitation and the impact it could have on people's lives. For example, based on Shea et al.'s (2019) findings, one of two managers in Canada thought people affected by cancer should be more active physically, but did not know how this could be achieved. Another manager suggested more research on cancer rehabilitation and exercise before the implementation of such services. This indicated a lack of knowledge on the part of hospital authorities. Similarly, management's knowledge was found to be an issue in the UK. Rehabilitation commissioners reported that funding bodies often lacked knowledge of cancer rehabilitation. This lack of knowledge was observed even after

financial support was provided for cancer rehabilitation service implementation (Transforming Cancer Services Team 2017b). This often resulted in funding being reduced after initial support. One commissioner suggested organising service walkthroughs for funders (Transforming Cancer Services Team 2017b). However, hospital administrators often had to make hard choices even if their knowledge was up to date on cancer and rehabilitation. Due to limited financial resources, other services often enjoyed priority over cancer rehabilitation (Shea et al. 2019, Smith-Turchyn et al. 2016).

One of the reasons for healthcare professionals' lack of knowledge was the evidence-practice gap (Baker et al. 2015, Beidas et al. 2014, Dennet et al. 2020, Fong et al. 2018, Granger et al. 2016, Handberg et al. 2018, Jakobsson et al. 2008). There is emerging evidence that cancer rehabilitation, exercise and lifestyle change are effective in maintaining and improving quality of life during and after treatments (Lavallée et al. 2019, Payne et al. 2018), good for mental and physical health (Bourke et al. 2018, Browall et al. 2018, Clifford et al. 2018, Mitdgaard et al. 2015) and help people cope with their diagnosis (Yannitsos et al. 2020). However, this evidence does not always seem to translate into clinical practice. One reason could be the dissemination of research findings. Some newer evidence is only published in profession-specific journals therefore precluding wider access (Granger et al. 2016). Moreover, the evidence-base has developed quite substantially in recent years, and professionals often indicated they could not keep up with the changes (Neher et al. 2020, Olsson Moller et al. 2020). This often resulted in a clear 'evidence-practice gap' (Neher et al. 2020, Shea et al. 2019), meaning that while evidence to support rehabilitation existed, it was not always implemented in practice. One way to embed evidence into everyday practice is the publication of evidence-based guidelines (Olsson Moller et al. 2020). However, healthcare professionals often reported that guidelines regarding cancer rehabilitation, exercise, or lifestyle change were too vague or general (James-Martin et al. 2014, Neher et al. 2020, Kenyon et al. 2020).

Healthcare professionals' insufficient knowledge and the evidence-practice gap has led to a lack of consensus within the rehabilitation and therapy discipline. As seen in chapter 2, there is a lack of consensus on the definition of cancer rehabilitation. Indeed, in this qualitative synthesis, some HCPs thought rehabilitation was only post treatment, while others could not even place rehabilitation within the cancer pathway for certain conditions (McCartney et al. 2011). Moreover, there is an absence of consensus on the right time for referral to cancer rehabilitation or exercise (Bourke et al. 2018, Fong et al. 2018, Granger et

al. 2016). This was particularly noticeable between nurses and physicians. Fong et al. (2018) reported that nurses were more likely to give information about exercise or refer people to rehabilitation as soon as possible, while physicians often waited until post treatments.

In addition, there was a lack of professional consensus on who should provide information, practical support, or referral. Nurses were often seen as care coordinators; therefore, many professionals thought nurses provided information and dealt with referrals to other services (Bourke et al. 2018, Carter et al. 2014, Granger et al. 2016, Jakobsson et al. 2008). However, information on exercise was often seen as a role for a physiotherapist or an exercise trainer (Bourke et al. 2018). Differences in opinions on professional roles often led to insufficient information and referrals, particularly if professionals did not think providing information had any relevance to their roles (Baker et al. 2015, Beidas et al. 2014, Handberg et al. 2018, Ijsbrandy et al. 2020, Neher et al. 2020). Moreover, cancer rehabilitation and exercise were often seen as an add-on by healthcare professionals. Therefore, referring to services or provision of information were often absent in consultations, unless people pushed for it (Dennet et al. 2020, Handberg et al. 2018, James-Martin et al. 2014, Olsson Moller et al. 2020). However, as previously mentioned in this PhD thesis (section 3.3.7.1) information provision and referring people to rehabilitation and exercise interventions should be every healthcare professional's business (Baker et al. 2015, Dennet et al. 2020, Granger et al. 2016, Handberg et al. 2018, Romero-Elías et al. 2020).

#### *3.4.6.2 Service delivery and organisation*

This theme contains five subthemes representing five different barriers that impact on the delivery of cancer rehabilitation services. The first subtheme explores the insufficient integration of cancer rehabilitation services. As mentioned above (section 3.4.6.1), cancer rehabilitation and exercise interventions were often seen as add-ons. Moreover, insufficient evidence-based guidelines meant services were not integrated into the cancer pathway. Thus, people affected by cancer could have finished treatments without seeing a rehabilitation expert, even if they had rehabilitation needs (Fong et al. 2018, Granger et al. 2016, Handberg et al. 2018, Jakobsson et al. 2008, Olsson Moller et al. 2020). Referrals and counselling were ad hoc, leaving some people without help (Shea et al. 2019).

This lack of integration was made worse by the breakdown of communication between different healthcare teams (Ijsbrandy et al. 2020, Jakobsson et al. 2008, Neher et al. 2020,

Olsson Moller et al. 2020, Santa Mina et al. 2015). Ijsbrandy et al. (2020) investigated exercise programmes within a shared-care model by examining primary and secondary care services in The Netherlands. They found that information sharing between the two levels of care provision was not optimal.

Another subtheme and a reason for cancer rehabilitation service delivery problems was issues with funding. How cancer rehabilitation services should be funded has been an issue worldwide. In the USA, insurance coverage has been problematic (Beidas et al. 2014). In the UK, programmes are often funded by third sector parties, and NHS funding is questionable (Bourke et al. 2018). However, regardless of country of origin, many of the studies commented on funding as an issue. Without funding, services cannot be implemented, as labour costs, overheads (depending on the setting) and equipment needed to be paid for. As seen above, the reason for the lack of funding could be multi-layered. Hospital managements' insufficient knowledge on cancer rehabilitation, rehabilitation treated as add-on instead of being integrated into the cancer pathway could all influence funding.

Not having sufficiently trained staff to provide cancer rehabilitation, advice or exercise programmes was found to be a barrier in several studies (Denner et al. 2020, Granger et al. 2016, Ijsbrandy et al. 2020, McCartney et al. 2011). Moreover, the lack of AHPs employed was also problematic, as they are best placed to provide information on exercise and diet (Granger et al. 2016). There was a need for professionals with specialist preparation to provide tailored care to people affected by cancer. As mentioned above, clinicians often lack the specialist knowledge to provide information or referral; therefore, increasing specialist capacity and upskilling healthcare professionals could be a possible solution.

Inadequate staffing levels and skill mix meant professionals had insufficient time to provide information, referral, or practical support to people affected by cancer (Baker et al. 2015, Beidas et al. 2014, Carter et al. 2014, Fong et al. 2018, Granger et al. 2016, Handberg et al. 2018, Ijsbrandy et al. 2020, Jakobsson et al. 2008, James-Martin et al. 2014, McCartney et al. 2011, Romero-Elías et al. 2020, Shea et al. 2019, Smith-Turchyn et al. 2016, Transforming Cancer Services Team 2017b). During consultations, healthcare professionals only had time to talk about treatments and matters relevant to their professions. If they provided information on rehabilitation, or exercise, that was often generic. Having a lack of time led to people affected by cancer not raising issues, as they did not want to burden their healthcare professionals.

### 3.4.7 What are the facilitators of cancer rehabilitation service provision from healthcare professionals' perspectives?

From the 21 qualitative studies reviewed three themes were derived that reflected the facilitators of cancer rehabilitation service provision, namely: multidisciplinary working, and education and training.

#### 3.4.7.1 *Multidisciplinary working*

As discussed in chapter 2, rehabilitation is holistic by its nature. However, the medical model continues to dominate cancer care. The view that rehabilitation is an add-on and not integral to the cancer pathway serves as a barrier to enabling people to manage the long-term and late effects of cancer and its treatments. Arguably, a multidisciplinary approach is needed to enable people affected by cancer to live as good a life as possible. However, as mentioned in the previous section, lack of knowledge, time, and communication between professionals led to lack of referrals to rehabilitation, practical support and information provision to people affected by cancer. Furthermore, supporting people affected by cancer is everyone's business. The more healthcare professionals from different disciplines work seamlessly together as a united team, the more likely people's rehabilitation needs will be met (Bourke et al. 2018, Carter et al. 2014, Dennet et al. 2020, Granger et al. 2016, Jakobsson et al. 2008, McCartney et al. 2011, Olsson Moller et al. 2020).

In addition, rehabilitative interventions, such as dietary advice, exercise or psychological support should be provided as one programme and not in separate places. This could improve access and increase the likelihood that people will adhere to their plan of care (Fong et al. 2018). Moreover, healthcare professionals should be working together to ensure, messaging regarding rehabilitation and lifestyle change is consistent, and people do not receive conflicting information (Baker et al. 2015, Dennet et al. 2020, Granger et al. 2016).

#### 3.4.7.2 *Education and training for healthcare professionals*

To achieve effective multidisciplinary working, training and upskilling healthcare professionals is necessary (Bourke et al. 2018, Carter et al. 2014, Dennet et al. 2020, Fong et al. 2018, Granger et al. 2016, McCartney et al. 2011, Transforming Cancer Services Team 2017b). Educating the entire multidisciplinary team has been suggested (Dennet et al.

2020; Granger et al. 2016), while Fong et al. (2018) advocated that rehabilitation and exercise prescription should be included in medical education in Canada. Bourke et al. (2018) suggested the development of training packages for healthcare professionals in the UK. Regarding exercise prescription and exercise-based rehabilitation, Granger et al. (2016) argued that physiotherapists are best placed to educate other professionals in the UK. Moreover, presenting up to date quality evidence on rehabilitation, exercise and lifestyle change can enhance engagement of the multidisciplinary team in providing information and referrals to rehabilitation services (Shea et al. 2019).

Healthcare services, that are research active with regard to cancer support and rehabilitation, are more likely to have enhanced knowledge on exercise and practical support for people affected by cancer (Granger et al. 2016). Furthermore, hosting rehabilitation and exercise programme clinical trials supports the embedding of research protocols into clinical practice (Santa Mina et al. 2015), while continuous data collection in established services could attract further funding (Shea et al. 2019). In addition, Payne et al. (2018) found that healthcare professionals, once participated in trials, were keen to learn from the findings and apply it to future service developments.

#### **3.4.8 Summary of the qualitative synthesis**

The findings of the qualitative synthesis suggest that healthcare professionals' insufficient knowledge, and issues with service delivery and organisation are a barrier to cancer rehabilitation service provision. Within the theme of service delivery and organisation, further issues were detected including issues with staff capacity and funding. Multidisciplinary team working and healthcare professionals' education can facilitate the provision of cancer rehabilitation.

### **3.5 Limitations of the literature reviews**

To provide transparency, the limitation of the overview of qualitative research reviews and the qualitative synthesis is discussed. Only one person, the author of this thesis, conducted the literature search, selection, and review process, which could lead to potential bias. Although the results of the review were discussed with the supervisory team, potential bias could not be fully excluded.

Only papers in English language were included in the above two literature reviews, which could mean that information published in languages other than English were missed. Research was mainly focused on exercise and exercise-based rehabilitation; therefore, the results might not be representative of other rehabilitative interventions, such as mindfulness therapy, counselling or speech and language therapy. Although the aim was to include research regarding speech and language therapy, no research papers were retrieved with this AHP population. A possible explanation could be that search terms need to be broadened and other search engines should be scanned as well. However, it is likely that there is a lack of qualitative research in the field of oncology speech and language therapy. Therefore, speech and language therapy is a potential area for further research. Moreover, the included papers mainly considered dietary advice from the perspective of weight gain. However, dietitians have a much wider role in rehabilitation. Further qualitative research about the role of dietitians in cancer should be explored.

In addition, papers were retrieved from several different countries. However, out of the 21 qualitative studies and the nine qualitative reviews, only one paper had ties to Wales (McCartney et al. 2011). Furthermore, the study only focused on people affected by brain tumour and did not give indication of any other cancer diagnoses. Therefore, there is a need for research investigating the barriers and facilitators of cancer rehabilitation in Wales.

### 3.6 Conclusion

The overview of reviews and the qualitative synthesis summarise the barriers and facilitators of cancer rehabilitation, highlighting issues, such as challenges unique to the person affected by cancer, insufficient information for people affected by cancer, professional's lack of knowledge, and service delivery. These barriers could be overcome by multidisciplinary team working, healthcare professionals' education, the provision of individualised, tailored care, and supportive environment for people affected by cancer. The barriers and facilitators identified in these two literature reviews provide a rich basis for the development of initial programme theories (IPTs) that can be empirically tested with data collection following a realist evaluation methodological framework. The next chapter introduces realist evaluation and the IPTs influenced by the findings of these literature reviews.



## Chapter 4: Realism, realist evaluation, and realist-informed evaluation

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To explore what works in two cancer rehabilitation services, for whom, in what circumstances and how, realist evaluation was identified as an appropriate methodological framework to guide the study design and conduct. To understand why realist evaluation is a good fit to guide this PhD, it is important to introduce the realist philosophical standpoint. Moreover, as realist evaluation is a complex methodological framework, its key components need to be described as does the way in which it was conducted in this PhD study. In this chapter, firstly the underlying philosophical background of realism is considered, and the key components of realist evaluation are described. Then the initial programme theories (IPTs), which provided the basis for this investigation, and their development are presented. Finally, it is discussed what changes were made to the realist evaluation methodological framework, and why a realist informed evaluation was conducted.


### 4.1 Overview of realist research philosophy

Research methodology is greatly influenced by the philosophy of science. Therefore, it is important to discuss the philosophical standpoint of this PhD study. Different schools of science philosophy exist with different views on the existence of the world and reality (ontology), and how this reality can be understood (epistemology) (Greenhalgh et al. 2017a). Realist evaluation is a methodological framework originating from realism (Pawson and Tilley 1997). Realism sits between positivism and constructivism, the two polar ends of science philosophy (Greenhalgh et al. 2017a). These different schools of the philosophy of science are briefly summarised in Table 7 to provide an overview of the difference between them.

What makes realism an independent school of science philosophy is its ontological depth. Realism states that the real world exists (Greenhalgh et al. 2017a). However, there is interdependency between what is real and people's interpretation of reality (Westhorp et al. 2011). How people interpret reality influences their actions, which can have a real effect on the world (Westhorp et al. 2011). This interdependency is a result of the stratified nature of social reality. The stratified nature of reality means the embeddedness of human action in the social world. Human action makes sense when social interactions, politics and

rules that could influence it are considered (Pawson and Tilley 1997, Kazi 2003). In addition, the stratified reality incorporates the concept of emergence (Kazi 2003). Emergence holds that the stratification of causal elements can generate new phenomena (Kazi 2003). Therefore, the environment, in which interventions are implemented, is constantly changing, sometimes due to the inter-relation between the intervention effect and the reality altered by it (Pawson 2006). The real world is an open system, where numerous factors can influence how an intervention works.

Table 7 Brief summary and comparison of science philosophy (Westhorp et al. 2011, Greenhalgh et al. 2017a)

Positivism	Realism	Constructivism
		
Ontology		
<ul style="list-style-type: none"> <li>Reality is objective and exists independently from human observation and understanding</li> </ul>	<ul style="list-style-type: none"> <li>Real world exist, but there is interdependency between real and people's interpretation: stratified nature of social reality</li> </ul>	<ul style="list-style-type: none"> <li>No clear ontology; if it exists at all, reality is subjective, and it is both individually and socially created</li> </ul>
Epistemology		
<ul style="list-style-type: none"> <li>Scientific truth exists, and final knowledge can be achieved through research and observations</li> </ul>	<ul style="list-style-type: none"> <li>No final knowledge exists due to the stratified nature of social reality, but achieving partial knowledge might be possible</li> </ul>	<ul style="list-style-type: none"> <li>Considered more of a philosophy of knowledge (epistemology) concerned with experience and meaning</li> </ul>
Approach		
<ul style="list-style-type: none"> <li>Quantitative</li> </ul>	<ul style="list-style-type: none"> <li>Qualitative, quantitative, or mixed methods</li> </ul>	<ul style="list-style-type: none"> <li>Qualitative</li> </ul>

However, considering the world to be an open system that is constantly changing from interactions between people, interventions and their effects on reality raises the question of how knowledge can be generated. Scientific research, particularly randomised controlled trials which are considered gold standard in healthcare, aims to investigate interventions in closed systems to avoid the influence of confounding factors (Pawson 2006, Dalkin et al. 2015). However, from a realist point of view research in a closed system is not possible. The question of how to generate knowledge divided realists into two branches: critical (Bhaskar 1979) and scientific realism (Pawson and Tilley 1997). Bhaskar (1979) argued that social science and research could not be conducted in a closed system. As an alternative to a closed system, Bhaskar (1979) proposed that critical realists need to choose a moral

standpoint prior to the commencement of the research and critically investigate the possible findings from that perspective. In contrast, scientific realism claims that research does not need to achieve closed system conditions or provide alternatives. Instead, scientific realists accept that knowledge on a programme in an open system will always be partial (Pawson 2006, Dalkin et al. 2015). Realist evaluation originates from scientific realism (Pawson and Tilley 1997).

This scientific realist standpoint, which thrives in open system research, is what makes realist evaluation suitable to guide the investigation of cancer rehabilitation services in South Wales. The services are based on scientific evidence that show the positive impact of cancer rehabilitation in closed systems, such as randomised controlled trials (RCTs) where factors that could influence interventions are accounted for. However, as WCPES data shows, people still have unmet rehabilitation needs (Welsh Government 2014b, 2017). This indicates that when the rehabilitation services were implemented in the open systems of the hospitals, they did not work as originally expected. Therefore, scientific realism was a suitable choice for this PhD study as it can investigate services in open systems. In the next section realist evaluation by Pawson and Tilley (1997) is detailed, which follows the scientific realist line of research.

## 4.2 Realist evaluation by Pawson and Tilley

Realist evaluation was developed by Pawson and Tilley (1997) to explore how exactly an intervention works in different circumstances. It seeks to answer a specific question of “what works for whom in what circumstances and how” which can help uncover the operation of interventions set in the open system (Pawson & Tilley, 1997). Realist evaluation has a unique way in which it understands causation. Realist evaluation holds that interventions naturally have causal powers, although these powers only result in change if they meet the right circumstances (Dalkin et al. 2015). This is different from the successionist causation that is provided by experimental designs (Dalkin et al. 2015). Pawson and Tilley (1997) refer to causal powers as mechanisms and state that how interventions produce outcomes can be explained with the configuration of mechanism and context. Thus, the unit of analysis in realist evaluation is context-mechanism-outcome (CMO) configurations. Although the core concepts of realist evaluation have been introduced in chapter 1 (section 1.4.1), deeper insight into the mechanism, context and outcomes is provided below.

#### 4.2.1 Mechanism

Mechanisms are the elements of an intervention that can result in behaviour change and certain outcomes. Realism holds that interventions always have mechanisms or underlying causal powers, although they only work in the right context. Mechanisms can be further divided into resources and reasoning (Dalkin et al. 2015). Resources are the elements of the intervention that participants react to. Reasoning is the participants' thinking or response triggered by the existing resources. Although resources are part of the mechanisms, the participants' decision-making will create outcomes (Dalkin et al. 2015).

Qualitative methods are often used to explore mechanisms, their underlying resources, reasoning, and relationship to context. Pawson and Tilley (1997) advise the use of qualitative interviews to investigate mechanisms and unexpected contexts and outcomes. In medical education research, Wong et al. (2012) suggest that the best way to learn how and why an intervention works is to interview service providers and service users. That way information can be gained from two different perspectives, which can help thoroughly understand the mechanisms. Talking to different stakeholders can also help with outlining the relationship between contexts and mechanisms. In this PhD study qualitative semi-structured interviews were conducted with both service providers (healthcare professionals) and service users (people affected by cancer who attended the cancer rehabilitation services) to investigate the underlying mechanisms of cancer rehabilitation.

#### 4.2.2 Context

The success of an intervention always depends on the context it is implemented in (Pawson and Tilley 1997). Following the logic of realist evaluation, mechanisms will only result in desired outcomes if the context is right (Pawson and Tilley 1997). Context does not simply refer to the setting in which an intervention is implemented in, but how the setting works (Greenhalgh et al. 2017d). Context can be policy, social factors, values or beliefs, anything that can support or inhibit the mechanisms from working (Greenhalgh et al. 2017d). When thinking about context it is important to consider for whom the intervention works, where, and when. The population, the intervention is targeted towards, can have a great effect on its transferability to different settings (Westhorp 2014). Gender, spirituality, mental capacity, culture, class, and status of the potential participants can all have an effect on how an intervention works. Moreover, interventions have the potential to change the

context over time, which means the mechanism might also need to change and accommodate to the new context it created. This changing reality is in line with the concept of emergence (Pawson and Tilley 1997).

To investigate contexts both quantitative and qualitative methods can be used (Pawson and Tilley 2001). Qualitative methods are particularly useful when the evaluator looks for new or different contexts (Pawson and Tilley 2001). In this PhD study, qualitative interviews from both the perspectives of people affected by cancer and healthcare professionals were conducted. The two perspectives can complement each other and highlight contexts that would not be possible from interviewing only one group of stakeholders.

#### 4.2.3 Outcome

In realist evaluation outcomes are not simple, pass or fail verdicts of the effectiveness of an intervention (Pawson and Tilley 1997). Outcomes are the results of the interaction of numerous mechanisms and contexts (Pawson and Tilley 1997). To determine outcomes, quantitative methods are often used, although qualitative methods can shine light on outcomes of the investigated intervention (Westhorp et al. 2011). In this PhD study, to determine the outcomes secondary analysis of routinely collected outcome measure data and qualitative interviews were conducted.

#### 4.2.4 CMO Configurations

The creation of these configurations requires complex analytical skills and abstract thinking. In research the two most frequently used reasoning are inductive and deductive (Greenhalgh et al. 2017c). Inductive reasoning draws conclusions from data collected, while deductive logic tests pre-existing hypotheses to accept or reject them (Greenhalgh et al. 2017c). Inductive logic is mostly used in constructivist and/or qualitative research. Deductive logic is the pillar of positivist research philosophy and quantitative research. Realism and realist evaluation stands out, because the scientific reasoning used to identify CMO configurations is retroduction (Kazi 2003). Retroduction allows the researcher to investigate the hidden causal powers or mechanisms behind observable outcomes (Greenhalgh et al. 2017c). It uses both inductive and deductive reasoning along with the researcher's insights, expertise, and abstract thinking. As mentioned above, both quantitative and qualitative data can be used in realist evaluation, which allows the use of inductive and deductive logic.

Realist evaluation is theory-driven, which means it usually starts with deductive logic (Greenhalgh et al. 2017c). An initial programme theory (IPT) based on provisional CMO configurations is set up, which is tested throughout the evaluation process (Pawson and Tilley 1997). IPTs are middle-range theories that are developed through literature review, document analysis and engagement with service providers or experts (Pawson and Tilley 1997). Middle-range theories are empirical hypotheses that are turned into broad statements that can be tested, verified, refuted or refined by data (Merton 1968). During data collection and data analysis with the mixture of inductive, deductive and retroductive reasoning new CMO configurations are developed (Greenhalgh et al. 2017c). However, due to the ever-changing nature of reality, which is embedded in social processes a final truth can never be achieved in realist evaluations (Kazi 2003). CMO configurations can always be further explored and refined with new knowledge. Therefore, realist evaluation begins and ends with middle-range theory.

### 4.3 Development of initial programme theories

Interventions are often developed based on underlying abstract theories, such as behaviour change theories, which can explain how they work (Shearn et al. 2017). These abstract theories should be detailed in intervention protocols and documentation and could be used to develop IPTs (Shearn et al. 2017). However, real life interventions are often messy, lacking an explicit abstract theory, and more focused on the outcome of interest than on how they work (Shearn et al. 2017). Shearn et al. (2017) distinguished four strategies that can be used to develop IPTs in the absence of explicit abstract theories in the intervention documentation. The first strategy uses abstract theories taken from comparable interventions. The second strategy utilises abstract theories that were purposively chosen by the research team but not mentioned in the literature about the intervention under investigation. The third strategy includes using literature reviews on similar interventions to build tacit theories in the absence of formal abstract theories. The fourth strategy involves development of new tacit theories driven by data, such as programme architect interviews. Programme architects are the developers or leaders of the intervention under investigation (Pawson and Tilley 1997).

In this PhD study, a mixture of Shearn et al.'s (2017) strategies were used to build IPTs, as policy papers and guidance had insufficient explicit information on underlying abstract theories that informed cancer rehabilitation service provision. These strategies included

building tacit theories based on the literature, tacit theories based on discussions with programme architects, and finally using abstract theories from comparable interventions in the literature. Initially, IPTs based on tacit theories were developed by using literature reviews and policy documents. These IPTs were presented to the Steering group who provided the programme architect perspective.

#### 4.3.1 The role of the Steering group in developing initial programme theories

This PhD study had a dedicated Steering Group from the beginning. The Steering group included a patient involvement facilitator, the supervisory team, representatives from Macmillan Cancer Support, and the two Therapy Teams (both Willow and Fern). The Steering group provided the clinical and third sector perspective to this study. As the Steering group members were experts in the field of oncology and cancer rehabilitation, they had insight into how cancer rehabilitation services worked and could contribute to building IPTs as programme architects. The use of steering groups to develop theories for realist and realist informed evaluations has been supported by the literature. Punton et al. (2020) recommended using steering groups for theory development purposes, as this was an efficient way to involve busy programme architects.

For this PhD study, Steering group meetings were organised quarterly. At the second Steering group meeting (13<sup>th</sup> September 2017) provisional IPTs based on tacit theories from the literature were presented to the expert members. The proposed IPTs were discussed, and the Steering group members made recommendations for changes, so that IPTs better reflected how the experts believed cancer rehabilitation services worked. Extensive handwritten meeting notes were made, which were typed up in Microsoft Word. Following the Steering group meeting, I considered the experts' recommendations, and made changes to the potential IPTs accordingly. Recommendations included the amalgamation and reconsideration of two theories regarding a common assessment tool (context 1), assessment of people's needs (context 2), improved quality support (mechanism 1), individualised care (mechanism 2), earlier intervention (outcome 1), and person-centredness (outcome 2). Moreover, Steering group members recommended relevant literature and guidance. An extract from the meeting notes relating to these recommendations can be seen below.

*“SGM5<sup>6</sup> advised to combine the first two programme theories, because they are closely linked. She asked the question if a highlighted assessment tool was found in the literature. The student replied that based on the Network Cancer Rehabilitation Leads Report 2013, every Health Board uses a different assessment tool. SGM5 made a link to the Cancer Delivery Plan (CDP), which states that every patient should be assessed and have Holistic Needs Assessment and a care plan.”*

Modified IPTs were presented at the third Steering group meeting (17<sup>th</sup> January 2018). During this meeting, some conversations focused on the provisional IPT which later became IPT\_1. Steering group members discussed the influence people’s perception of rehabilitation and professional roles can have on their willingness to participate in interventions aimed to help them with their treatment related side effects.

*“SGM4 stated that the language we use is also important. Rehabilitation might not mean the same for everyone. SGM5 added that patients sometimes do not understand healthcare professional roles either. For example, occupational therapists are sometimes associated with return to work. Patients who have not been working for years and are confused about different healthcare services might not understand the role of an occupational therapist in their lives.”*

Moreover, Steering group members suggested abstract theories, such as patient activation that could inform the IPTs.

*“SGM3 also suggested that patient activation and readiness for change should also be considered when talking about rehabilitation. SGM3 stated that patients might not like the thought of rehabilitation if they are not ready for it.”*

These recommendations led to the development of the final IPTs which were presented at the fourth Steering group meeting (11<sup>th</sup> April 2018). While the provisional IPTs first presented to the Steering group in September 2017 were only tacit theories, the final IPTs were made with consideration to abstract theories.

#### 4.4 Abstract theories and models informing the initial programme theories

As mentioned above, patient activation was identified as an abstract theory that could explain how cancer rehabilitation services work and inform IPTs. Besides patient activation

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<sup>6</sup> SGM is short for Steering group member. Names were removed from the original meeting notes to maintain confidentiality. Numbers were allocated to Steering group members, to enable differentiation.



(Hibbard and Gilburt 2014), two other abstract theories were identified via other routes: self-determination (Ryan and Deci 2000), and the biopsychosocial model (Engel 1977). Self-determination theory was identified as a building block of IPTs by using theories from other comparable interventions (Shearn et al. 2017). Self-determination theory has been used in cancer rehabilitation to inform intervention development (Behzadnia et al. 2020) and to make sense of what motivates people to participate (Wilkinson et al. 2017). The biopsychosocial model as an abstract theory was identified via the scoping review of cancer rehabilitation definitions in chapter 1, as cancer rehabilitation is defined as holistic, including not only the physical aspect of health, but the psychological and social domains as well. These abstract theories are described in more detail below.

#### 4.4.1 Patient activation

Patient activation is a behavioural change concept focusing on factors that could lead to people's active engagement and participation in their own care (Hibbard and Gilburt 2014). These factors include people's knowledge, skills, and confidence that are needed for successful management of their health issues and care (Hibbard and Gilburt 2014). Patient activation is related to the concepts of self-efficacy, readiness for change, and health literacy, although it is broader and more generalised, enabling its use in a wider healthcare setting. Based on the logic of patient activation, the more activated a person is, the more likely that they are involved in their care and make positive health behaviour changes. Activated individuals adhere to treatment and health related interventions more consistently than less activated. People who are less activated are less likely to have problem-solving abilities regarding their health condition or have confidence in their skills to manage their own health, thus failing to actively engage in their care or make beneficial health behaviour choices (Hibbard and Gilburt 2014). Moreover, less activated people usually have more unmet health needs.

Patient activation can be developed and improved to reduce unmet health needs and to help people self-manage their condition. Hibbard and Gilburt (2014) advises the use of individualised, tailored care to increase people's level of activation. Achievable goals meaningful to the individual should be set with healthcare professionals, and interventions should be offered to help people work towards these goals. Achieving a set goal can help people gain confidence and increase their activation level. Interventions that can help

increase patient activation include learning new skills, educational classes, peer support, and programmes aiming to promote ownership over health management.

The concept of patient activation fits with cancer rehabilitation, as discussed in chapter 2, cancer rehabilitation aims to enable people to achieve maximal functioning. The emphasis is on “enabling” implying that people affected by cancer need to be active to achieve maximal functioning, and healthcare professionals can provide help with this. Moreover, as explored in section 3.3.7, individualised and tailored cancer rehabilitation can help people achieve their goals and increase their self-efficacy and confidence, thus working towards patient activation. A mixed methods evaluation of a comprehensive cancer rehabilitation programme (one-to-one or group interventions including a 4-week health education and/or 6-week exercise intervention based on the person’s choice) demonstrated that patient activation improved by 19.2% (Sumner and Hughes 2018). Therefore, the concept of patient activation can potentially explain how cancer rehabilitation works.

#### 4.4.2 Self-determination theory

Self-determination theory is a unique approach to understanding human motivation and behaviour change (Ryan and Deci 2000). Self-determination theory holds that for people to develop and maintain a new behaviour, the values and skills needed for change need to be internalised by the individuals. This process of internalisation can be maximised by fulfilling three psychological needs: autonomy, competence, and relatedness (Ryan and Deci 2000). Autonomy relates to volition, that the required behaviour is in line with the individuals integrated values, beliefs and sense of self (Deci and Ryan 2000). Competence refers to the skills and confidence needed for change, while relatedness means the human connections needed to support adoption of new behaviours (Ryan and Deci 2000; Ryan et al. 2008). In addition to behaviour change, satisfaction of these three needs could lead to improved mental health and quality of life (Ryan et al. 2008).

While all three psychological needs have to be satisfied for behaviour change and its maintenance, autonomy is a prerequisite. People only learn skills and gain competencies once they volitionally act towards a new behaviour (Ryan et al. 2008). To further understand autonomy, its relationship to motivation must be discussed. Motivation could be intrinsic and extrinsic, depending on what drives the person to engage in an activity or behaviour (Ryan and Deci 2000). Intrinsic motivation drives activities that cause enjoyment

and people have a natural inclination towards, while extrinsic motivation could refer to working towards the achievement of an outcome. Extrinsic motivation could be separated into two categories: controlled and autonomous motivation. In controlled motivation, people usually act due to demand from an outside authority (external regulation) or to receive praise or avoid guilt (introjection). In autonomous motivation, people value the importance and benefits of a behaviour change (identified regulation), or they fully align with it and integrate it into their lifestyle (integrated regulation) (Ryan et al. 2008). In summary, the more autonomous people's motivation and behaviour choices are, the more likely that changes made will be maintained.

Within healthcare, people's autonomy can be supported by offering relevant information and rationale for the reason why behaviour change is needed (Ryan et al. 2008). Thus, helping people understand the importance and benefits of changing their behaviour, and initiating internalisation. To nurture new behaviours and help their maintenance, people's competence have to be developed by providing them with skills and tools necessary (Ryan et al. 2008). Feedback is important when learning new skills, and people should not be over challenged. Thus, skill training needs to be tailored to the individual (Ryan et al. 2008). In addition, relatedness can be satisfied by a supportive patient-professional relationship (Ryan et al. 2008).

As to how self-determination relates to cancer rehabilitation, the concept of autonomy, competence, and relatedness have been used to investigate and design new interventions to help people manage their cancer related health issues. Two cross-sectional studies, relating to exercise for people affected by colorectal cancer (Peddle et al. 2008) and a cancer rehabilitation programme containing different elements (Ohlsson-Nevo et al. 2019), discussed that interventions tailored to satisfy the three psychological needs could be beneficial in engaging people in their rehabilitation or in physical activity. Such tailoring could include information on the benefits of rehabilitation, teaching skills for people affected by cancer (autonomy and competence), providing a supportive environment either through peer support or relationship with professionals (relatedness) (Ohlsson-Nevo et al. 2008, Peddle et al. 2008). Behzadnia et al. (2020) found that an autonomy supportive exercise intervention (involving non-controlling coaching style, positive feedback, understanding the perspective of the person affected by cancer) increased the enjoyment and mastery of exercise in people affected by breast cancer. Wilkinson (2020) found that relatedness in the form of therapeutic relationships supported self-management behaviour

in people affected by cancer, although poor dissolution of these patient-professional connections could lead to unsatisfactory outcomes. In addition to cancer, self-determination theory has been found useful in understanding how cardiac rehabilitation interventions (Rahman et al. 2015), and exercise programmes for osteoporosis (Mack et al. 2017) work.

#### 4.4.3 Biopsychosocial model

Biopsychosocial model is a general model used in healthcare and medicine. It considers that health and disease is best understood by a combination of biological, psychological, and social factors (Engel 1977). Biological factors include physiology, anatomy, and genetics of the human body. Psychological factors refer to an individual's thoughts, feelings, and behaviours, while social factors include a person's socioeconomic status, culture, and environment. Understanding health and disease as a complex interaction between biological, psychological, and social factors fits well with the definition of cancer rehabilitation, as conceptualised in this thesis in chapter 2. Cancer rehabilitation aims to enable people and their families to achieve the goal of maximal physical, psychological, emotional, social, and economic functioning.

### 4.5 Initial programme theories

Based on policy documents, the literature reviews, the abstract theories introduced above, and discussions with the Steering group four IPTs were developed. These IPTs are discussed below by first mentioning some of the theories and literature that they were based on. Then the given IPT is introduced as a statement. Finally, the methods to test the IPT are briefly discussed.

#### 4.5.1 Information and awareness on cancer rehabilitation services

The literature review in chapter 3 highlighted that insufficient information on cancer rehabilitation and exercising can act as a barrier to people accessing needed rehabilitation support (Browall et al. 2018, Clifford et al. 2018). People affected by cancer often reported that they did not know what exercises to do or where to go to get help (Browall et al. 2018, Clifford et al. 2018). On the other hand, raising awareness of the benefits of exercise and participating in cancer rehabilitation can be a facilitator of people accessing services. Therefore, it was proposed that appropriate information instructing individuals where to go

for rehabilitation and what to do leads to increased uptake of cancer rehabilitation services. Information can increase people's knowledge and awareness on the purpose and availability of cancer rehabilitation, thus potentially activating people to engage with the services. Moreover, Ohlsson-Nevo et al. (2019) argued with the use of self-determination theory, that providing information and knowledge on cancer rehabilitation for people can lead to the satisfaction of competence.

However, information provision and having knowledge of cancer rehabilitation services do not necessarily translate into increased uptake. Other factors can influence uptake of services. For example, people's motivation, attitudes, and perceptions can act as barriers to accessing cancer rehabilitation services (Browall et al. 2018, Clifford et al. 2018, Fox et al. 2019, Lavalée et al. 2019, Granger et al. 2017). The literature reviews showed that people who did not enjoy exercising prior to their cancer diagnosis were less likely to engage in exercise-based cancer rehabilitation. From a self-determination theory perspective, this lack of enjoyment implies that some people may not have intrinsic or autonomous motivation to exercise. Thus, providing information on cancer rehabilitation services might not be enough. After consultations with the Steering group, it was decided that the context that facilitates information provision and raising awareness was people's perception and attitudes that were supportive of cancer rehabilitation. The full IPT is presented below:

**IPT\_1:** Raising awareness on available cancer rehabilitation services, and appropriate information on their purpose (**mechanism**) can increase the uptake of rehabilitation and scheme attendance (**outcome**) if people's perception and attitudes are supportive of cancer rehabilitation (**context**).

To test this IPT, both qualitative and quantitative data were used. First, the outcomes, which were the uptake and scheme attendance in cancer rehabilitation, were investigated. If issues with the uptake and scheme attendance had been identified, it would have indicated that information provision did not necessarily work. Either the context negatively affected the mechanism, or there were other mechanisms at play resulting in uptake issues. The outcome for IPT\_1, which was the uptake of the cancer rehabilitation service, was determined by the secondary analysis of the routinely collected database. Descriptive analysis of the number of people reported in the database over a four-year period (from 2014 to 2017) was conducted. In addition, to determine from the available data who attended the services, people's cancer diagnosis and gender was descriptively analysed.

Secondary analysis procedures are detailed in chapter 5. The secondary analysis only provided uptake information for the Willow Therapy Team. The Fern Therapy Team did not collect data on service uptake during the same period (from 2014 to 2017). Therefore, some of the interview findings were used to get an indication of the number of people accessing cancer rehabilitation by the Fern Therapy Team.

Mechanisms and contexts were tested through interviews with people affected by cancer and healthcare professionals. The qualitative interview procedures are detailed in chapter 6.

#### 4.5.2 Healthcare professionals training needs in the context of the four level model

The qualitative synthesis in section 3.4.6.1 showed that professionals' lack of knowledge and staff capacity, particularly the capacity of healthcare professionals with specialist training can be a barrier to provide cancer rehabilitation services (Dennet et al. 2020, Granger et al. 2016, Ijsbrandy et al. 2020, McCartney et al. 2011). Education and training of healthcare professionals can facilitate services provision. Therefore, it was decided that the mechanism of interest for this IPT was training needs assessment and training provision. Assessing training needs can identify gaps in the knowledge of the workforce, while training can help healthcare professionals gain the knowledge and confidence needed to provide a wide range of cancer rehabilitation interventions and services.

In the UK, and more specifically in Wales, the National Standards of the Welsh Government (2010) set out the model in which cancer rehabilitation services should be provided. The four level model presented in chapter 1 outlined levels in which cancer rehabilitation should be provided based on people's needs. At different levels healthcare professionals with different skillset are providing cancer rehabilitation. Therefore, this model can influence how training is provided for healthcare professionals at different levels. After consultation with the Steering group, it was decided that the context for this IPT was the four level model. The full IPT is presented below:

**IPT\_2:** To provide appropriate range and volume of rehabilitation services (**outcome**) that can meet the needs of people affected by cancer, healthcare professionals' training needs should be frequently assessed, and training should be provided (**mechanism**). Training availability is influenced by the level at which healthcare professionals work at based on the four level model (**context**) (NICE 2004, Welsh Assembly Government 2010).

To test this theory, qualitative interviews and secondary analysis were used. To determine the outcome, which was the range and volume of rehabilitation services, the routinely collected data from the Willow Therapy Team was used, as it had information on the exercise schemes people engaged in and how the exercise schemes changed over the years. In addition, qualitative interviews with healthcare professionals were used to map how the services changed over the years. Among the interviewed healthcare professionals there were managers and team leaders, who could provide an insight into how service provision developed. In addition, qualitative interviews were used to test the mechanisms and contexts.

#### 4.5.3 Individualised, tailored care based on a needs assessment tool

Based on the literature review, individualised and tailored cancer rehabilitation can facilitate people to access services (Fox et al. 2019, Lavalée et al. 2019, Michael et al. 2020, Granger et al. 2017). Different people have various needs, and challenges unique to them can require flexible services and planning of activities. Meeting achievable goals tailored to the individual with cancer can lead to improved confidence, self-efficacy (Lavalée et al. 2019, Michael et al. 2020) and “patient activation” (Hibbard and Gilbert 2014). This means people actively take part in their rehabilitation, thereby reducing their healthcare needs. Moreover, from a self-determination theory perspective, tailoring interventions to the individual, and avoiding over challenging can satisfy the psychological need of competence. The context that could enable the provision of individualised, tailored care is the use of needs assessment tools (NICE 2004, Welsh Assembly Government 2010). In this thesis, needs are considered from the biopsychosocial perspective, thus not only looking at physical, but psychological, and social needs. Based on the literature and the abstract theories the following IPT was agreed with the Steering group of this study:

**IPT\_3:** Dynamic, individualised, tailored cancer rehabilitation (**mechanism**) can lead to reduction in people’s healthcare needs (**outcome**) if care is based on routinely conducted health needs assessment (**context**).

To test this IPT, qualitative interviews with people affected by cancer and healthcare professionals was used. To see if people’s healthcare needs reduced qualitative interviews with people affected by cancer were used. People were asked questions regarding their symptoms and cancer treatment related side effects, and if anything bothered them about

their health post rehabilitation. The interview guide is presented in Appendix 10. To test the mechanism and the context interviews with both healthcare professionals and people affected by cancer were used.

#### 4.5.4 Accessible physical exercise, psychosocial and educational interventions

There is growing evidence that cancer rehabilitation has a positive impact on quality of life and can help manage cancer treatment related side effects (Hunter et al. 2017a,b). This could be achieved by satisfying the psychological need of competence by building up people's physical capacity to exercise or increasing their confidence to self-manage. However, accessibility of services can lead to people not attending cancer rehabilitation as travelling can be burdensome financially and regarding people's time (Granger et al. 2017, Yannitsos et al. 2020). Moreover, lack of trained multidisciplinary cancer rehabilitation professionals can result in limited availability of services. If services are not accessible and available, cancer rehabilitation cannot fulfil its aim to improve quality of life, and help people manage their symptoms and side effects. The below IPT was developed with the help of the above-mentioned literature and the Steering group:

**IPT\_4:** Accessible cancer rehabilitation, run by a trained multidisciplinary team with the capacity to see people in the region (**context**) can lead to enhanced quality of life and functional outcomes (**outcome**). In addition, cancer rehabilitation can help people with "getting back to normal" or with adapting to reduced capacities and fatigue (**outcome**). These outcomes could be achieved by building up and maintaining people's physical capacity and strength with physical exercise (**mechanism**) and improving self-management through psychosocial and educational interventions (**mechanism**).

To test the outcomes, which were improved quality of life and adaptation to issues, such as fatigue, both the secondary analysis and the qualitative interviews with people affected by cancer were used. The Willow Therapy Team collected outcome measure data pre- and post-rehabilitation, which was analysed with paired t-test or Wilcoxon signed-rank test depending on data distribution. Further details regarding the quantitative analysis are presented in chapter 5. As the Fern Therapy Team did not collect outcome measure data during the same period as the Willow Therapy Team, the qualitative interviews were used to investigate if people found rehabilitation provided by Fern beneficial. To test the contexts and the mechanisms, qualitative interviews with both people affected by cancer



and healthcare professionals were analysed. Qualitative interview procedures can be found in chapter 6.

## 4.6 Realist informed mixed-methods evaluation

As mentioned in section 4.1 and 4.2, both qualitative and quantitative research can be conducted as part of a realist evaluation. As mentioned above regarding the testing of IPTs, in this PhD study routinely collected quantitative data and qualitative interviews were used. The use of routinely collected data is widely accepted in realist evaluations (Greenhalgh et al. 2017b), while the preferred method of qualitative data collection is realist interviewing (Manzano 2016). Realist interviewing is distinct from qualitative interviewing as it is a theory-driven approach aiming to develop, test, or validate IPTs. In realist interviews theories can be explicitly tested by asking direct questions from programme architects about the logic of interventions (Manzano 2016). Moreover, people who receive an intervention can be more implicitly questioned about theories, as they are not responsible for the development services they use.

However, research accounts exist describing potential for confirmation bias or acquiescence while conducting realist interviews (Punton et al. 2016, Mukumbang et al 2019). Punton et al. (2016) considered cultural and funding related factors that could lead to interview participants agreeing with the presented IPTs, instead of discussing if they work and how. Moreover, Mukumbang et al. (2019) found during the pilot of their realist interview guide that programme architects tended to accept the theories without any discussion whether or not they worked in the real world. Thus, Mukumbang et al. (2019) decided to modify their realist interview guide. In addition, Mukumbang et al. (2019) found that they could not use realist interviewing with patient participants. Thus, they only presented microelements of theories to them.

These potential issues with the use of realist interviews led to the decision that in this PhD study a more conventional way of interviewing was used. While I still aimed to test the set IPTs, similar to Mukumbang et al. (2019) I only used microelements of these theories, and asked questions more implicitly. Furthermore, while the above mentioned four IPTs were set, I was also interested if other contexts or mechanisms influenced the outcomes. Therefore, I asked broader questions about barriers and facilitators of cancer rehabilitation. For these reasons I deviated from the realist evaluation methodological framework, thus

conducting a realist informed mixed-methods evaluation. However, I still followed the realist logic, and generative causation when interpreting and analysing data. Moreover, elements of realist interviewing, such as purposive sampling (Manzano 2016), and interviewing both service providers and users (Wong et al. 2012), were still followed. More details on how the qualitative interviews were conducted can be found in chapter 6.

## 4.7 Conclusion

This chapter detailed realist evaluation and its philosophical underpinnings, showing why it was a fitting methodological framework to guide this PhD study. The chapter summarised the key concepts of realist evaluation, such as context, mechanism, and outcome. Moreover, introduced the unit of analysis in realist evaluation, which is the context-mechanism-outcome configurations. The initial programmes theories (IPTs) were introduced which were tested through data collection and analysis and this will be discussed in more detail in the respective findings chapters. As realist evaluation supports the collection of both quantitative and qualitative data, mixed methods were used in this PhD study. The detailed methods used as part of the secondary analysis of the routinely collected data are presented in the next chapter.

## Chapter 5: Secondary analysis methods

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The Willow Therapy Team has been collecting patient reported outcome measures (PROMs) for their local database since 2014. People affected by cancer are asked to complete the PROMs before and after a 12-week long outpatient exercise and rehabilitation class. Depending on individual needs, people can attend hydrotherapy, Tai Chi, circuits or one-to-one therapy sessions with a physiotherapist or an occupational therapist (OT). The PROMs data are gathered to monitor change in rehabilitation participants' functional status, to provide person-centred care adjusted to individual needs and to investigate the possible impact of the exercise classes on quality of life. However, this data had not been comprehensively analysed. Therefore, the aim of this secondary analysis was to explore the routinely collected data and investigate change in functional and patient reported outcomes. In this chapter, I outline the methods I used to obtain and analyse data, and I discuss the psychometric properties of the outcome measures selected by the Willow Therapy Team.

### 5.1 Secondary analysis

Secondary analysis is the scientific investigation of data that was initially gathered for other purposes, such as patient registry (Cheng and Phillips 2014). I chose secondary analysis, because existing, real world data has been found to provide useful information on service impact, underuse, workforce capacity and patient population (Moen et al. 2017). In my thesis, this information provides the possible realist evaluation outcomes of cancer rehabilitation in South Wales. As mentioned earlier in the thesis, services can work differently in different contexts. Therefore, it is important to analyse local data from the Willow Therapy Team to develop CMO configurations that are relevant to South Wales.

The approach to secondary analysis was based on the eight-step guidance developed by Cheng and Phillips (2014) (Table 8), as it enables the thorough understanding of the strengths and weaknesses of the database. This is particularly important in realist evaluation because these strengths and weaknesses can imply what works and how in the services under investigation. However, before further discussing how secondary analysis was conducted, the ethical issues surrounding the use of routinely collected health service data must be considered.

Table 8 Steps of secondary analysis by Cheng and Phillips (2014)

<b>Eight steps of secondary analysis by Cheng and Phillips (2014)</b>
<p>Step (a) - Development of a statistical analysis plan.</p> <p>Step (b) - Thorough understanding of the strengths and weaknesses of the database, including reliability and validity of outcome measures, codebooks, guidebooks and other documents available.</p> <p>Step (c) - Generating operational definitions for variables.</p> <p>Step (d) - Generating frequency tables and cross-tabulations to identify categorical data codes, distributions and missing data.</p> <p>Step (e) - Recoding variables to handle missing data.</p> <p>Step (f) - Checking codes and identifier variables throughout the datasets to ensure they were recorded uniformly throughout data collection.</p> <p>Step (g) - Checking outcome measures to ensure the same interpretation was used throughout data collection.</p> <p>Step (h) - Applying design variables and multi-stage sampling used in the original data collection.</p>

## 5.2 Ethical considerations with the use of routinely collected patient data

Two of the main ethical concerns when using health service data are privacy and confidentiality. Routinely collected health service data can contain identifiable information. Depending on what type of information is needed for the purpose of the secondary analysis, different ethical procedures can be applied to protect affected individuals. (Tripathy 2013). However, these procedures can influence the quality of research, and thus require consideration (Mann et al. 2016).

If the data required does not contain any identifiable information, a full Health Research Authority (HRA) review is not necessarily needed, and individuals' consent does not have to be obtained. If there is identifiable information in the data, affected individuals' informed consent must be collected. However, this could be problematic. People might not want to give consent to the use of identifiable data for research purposes. People, whose data would be accessed, might have died and asking family members for consent might not be ethically appropriate or a practical possibility. Missing consent would result in data deletion. This could influence the research, resulting in involuntary selection bias (Mann et al. 2016). With the removal of data, vital information on the cohort could be lost and the remaining data might not be a true representation of the population (Mann et al. 2016). This could influence the generalizability of the findings.

In this study the original cancer rehabilitation database contained individuals' name, NHS number and, in some cases, postcodes. To access the database, written permission was obtained from the Willow Therapy Team. The terms of using the database for research was discussed with Information Governance of the local University Health Board. To access identifiable data, retrospective consent would have been needed. However, this would have resulted in data deletion, as some rehabilitation participants had died and that could have biased the findings of the analysis. Therefore, to avoid involuntary selection bias, it was agreed with Information Governance that all identifiable data, such as NHS numbers and postcodes, would be removed from the database to protect the identity of people who attended cancer rehabilitation. After permission from Information Governance was received to access the anonymised database, ethical approval for the study was granted by London - South East Research Ethics Committee (17/LO/2123) (Appendices 4 and 5). Subsequently, the database was obtained in Microsoft Excel format.

### 5.3 Thorough understanding of the strengths and weaknesses of the database

As part of secondary analysis, it is important to understand what variables and outcome measures were used, why and if they have been recommended for use in cancer rehabilitation. In this section the database and the measurement properties of the instruments chosen by the Willow Therapy Team are discussed.

The database contained the following information: cancer diagnosis; gender; type of exercise class attended; number of times people returned for a 12-week episode; outcome measures; and discharge codes. Outcome measures included: Functional Assessment of Chronic Illness Therapy – Fatigue (FACIT-F) scale (Yellen et al. 1997); Timed Up and Go Test (TUAG) (Podsiadlo and Richardson 1991); quality of life, pain intensity and shortness of breath (SOB) scales.

#### 5.3.1 Outcome measures

##### 5.3.1.1 *FACIT-F*

Fatigue is a common long-term effect of cancer and its treatment that could globally affect 62.1-74.8% of individuals with cancer (Roila et al. 2019; O'Regan et al. 2019). Therefore, examination of people's fatigue levels is important in clinical settings to provide therapies

that target individuals' needs. The Willow Therapy Team uses FACIT-F, to survey and measure their rehabilitation participants' fatigue. FACIT-F is a short, 13 item subscale of Functional Assessment of Cancer Therapy (FACT) questionnaire (Cella et al. 1993) developed to measure self-reported fatigue and its effect on people's activities of daily living (Yellen et al. 1997). Individuals need to rate 13 items on a scale of 0 to 4. Items include statements, such as 'I feel fatigued'. FACIT-F items are scored in reverse with the use of the formula in Figure 4. The summary score of the 13 items can range from 0 to 52. The score of 0 refers to the state of being very fatigued and 52 means no fatigue.

Figure 4 Scoring formula for FACIT-F; Source: <https://www.facit.org/FACITOrg/Questionnaires> [Accessed: 16.11.2019]

<u>Subscale</u>	<u>Item Code</u>	<u>Reverse item?</u>	<u>Item response</u>	<u>Item Score</u>
<b>FATIGUE SUBSCALE</b>	HI7	4 -	_____	= _____
	HI12	4 -	_____	= _____
	An1	4 -	_____	= _____
	An2	4 -	_____	= _____
	An3	4 -	_____	= _____
	An4	4 -	_____	= _____
	An5	0 +	_____	= _____
	An7	0 +	_____	= _____
	An8	4 -	_____	= _____
	An12	4 -	_____	= _____
	An14	4 -	_____	= _____
	An15	4 -	_____	= _____
	An16	4 -	_____	= _____
<p><i>Score range: 0-52</i></p> <p><i>Sum individual item scores: _____</i></p> <p><i>Multiply by 13: _____</i></p> <p><i>Divide by number of items answered: _____ = <b>Fatigue Subscale score</b></i></p>				

FACIT-F is widely used within oncology research to assess people's needs and to determine the effects of treatments. It has been found to have excellent test-retest reliability ( $n=44$ ;  $r=0.90$ ;  $p<0.05$ ) over several cancer diagnosis in the United States (US) (Yellen et al. 1997). Moreover, FACIT-F had excellent internal consistency measured in two cancer populations in the US ( $n$ =various; Cronbach's  $\alpha=0.93/0.95$  (Yellen et al. 1997)), ( $n=297$ ; Cronbach's  $\alpha=0.96$  (Butt et al. 2013)). FACIT-F has good convergent validity with Piper Fatigue ( $n=49$ ;  $r=-0.77$ ;  $p<0.05$ ), and Profile of Mood States (POMS) – Fatigue ( $n=49$ ;  $r=-0.83$ ;  $p<0.05$ ) (Yellen et al. 1997). This could indicate that FACIT-F measures a similar health construct as Piper Fatigue and POMS.

Roskovensky et al. (2013) investigated the concurrent validity of FACIT-F as a quality of life measure in a cancer rehabilitation population. FACIT-F was neither related to the physical domain of Short Form-36 (SF-36) ( $n=42$ ;  $r=-0.12$ ;  $p>0.05$ ), nor to the mental health ( $n=42$ ;

$r=0.07$ ;  $p>0.05$ ). This suggests that FACIT-F might measure a different element of quality of life than SF-36.

FACIT-F also has good known-groups validity (Yellen et al. 1997). It can differentiate between people affected by cancer who have anaemia with various haemoglobin levels ( $n=49$ ;  $F(2,46) = 3.59$ ;  $p<0.036$ ) (Yellen et al. 1997). In addition, FACIT-F has shown difference in fatigue levels of anaemic, non-anaemic cancer patients and the general population in the US ( $n=3415$ ;  $F(2, 3414)=1071.8$ ;  $p<0.001$ ) (Cella et al. 2002b).

Cella et al. (2002a) calculated the Minimal Clinically Important Difference (MCID) of FACIT-F. MCID is the smallest detected change in a measurement, which has value for patients (Jaeschke et al. 1989). MCID for FACIT-F has been established as 3.0 points change in the summary scores (Cella et al. 2002a).

Its good test-retest reliability, internal consistency, good convergent and known group validity makes FACIT-F a useful tool in assessing fatigue in people affected by cancer. However, FACIT-F did not correlate with SF-36, implying that it is not necessarily an indicator of quality of life (Roskovensky et al. 2013). In support of Roskovensky et al.'s (2013) findings FACIT-F is categorized as a unidimensional instrument, meaning it only measures physical symptoms, unlike multidimensional tests that examine the emotional and cognitive aspects of fatigue (Weis 2011). This could explain why FACIT-F was not correlated to SF-36. Weis (2011) describes cancer-related fatigue as a multifaceted problem, implying that its assessment needs a multidimensional approach. The Willow Therapy Team used FACIT-F in combination with other quality of life and patient reported tools (quality of life scale). This helped to provide a full picture of people's health and symptom burden.

#### *5.3.1.2 Timed up and Go (TUAG)*

With regards to cancer rehabilitation, people can often experience balance problems, cognitive impairments, and mobility issues as a result of cancer and its treatment (Kenyon et al. 2014). TUAG, the Willow Therapy Team's chosen measure, is a balance and functional mobility test. It is widely used in rehabilitation and falls prevention. During the test, individuals are asked to stand up from a sitting position, walk 3 metres, turn, walk back and sit down (Podsiadlo and Richardson 1991). The healthcare professional measures the duration of the full task with a stopwatch. Results are given in seconds.

Cut-off times exist for TUAG to help clinical decision making on the need for interventions. A commonly used cut-off time for TUAG is 13.5 seconds (Shumway-Cook et al. 2000). People who perform TUAG in 13.5 seconds or longer are likely to have balance or functional mobility problems.

Measurement properties of TUAG has been established in the cancer cohort. TUAG was reported to have an Intraclass correlation (ICC) of 0.88 in women who had breast cancer diagnosis ( $n=20$ ) (Wampler et al. 2007), thereby implying good intra-rater reliability.

Good convergent validity has been found between TUAG and Centre of Pressure (COP) excursion velocity measured with a force platform ( $n=40$ ;  $r=0.549$ ;  $p=0.012$ ) within a breast cancer population (Wampler et al. 2007). COP excursion velocity is a measure of postural stability and balance. Wampler et al.'s (2007) results imply that TUAG can measure postural stability, making it a feasible tool to use in clinical settings where force platforms are not necessarily available to investigate postural stability.

MCID has been established for TUAG in several health conditions, including stroke (2.59 seconds) (Flansbjer et al. 2005) and Parkinson's disease (11 seconds) (Steffen and Seney 2008). However, MCID has not been determined for any cancer diagnoses.

When interpreting TUAG results, another important feature of mobility and physical performance measures must be considered. When a physical test is performed multiple times, participants might naturally achieve better scores at each occasion regardless of any interventions. Improvement between measurements can be detected, because participants get familiar with the test and more confident in carrying it out. This phenomenon, when test performance improves without an intervention, is called practice effect (Hicks 2009). This could bias research results. Different techniques can be used to avoid the influence of practice effect. Several techniques have been reported with regards to TUAG (Bloch et al. 2017). These include performing one practice trial and a recorded trial (Shumway-Cook et al. 2000), calculating the mean of two trials (Lusardi et al. 2003) and the fastest of two or three trials (Bloch et al. 2017). The Willow Therapy Team reported the mean of three completed TUAG trials at each assessment to avoid practice effect.

TUAG has been found to have adequate intra-rater reliability and convergent validity as a functional mobility test in cancer (Wampler et al. 2007). However, there is a lack of research into other measurement properties of TUAG regarding cancer. The Oncology



Section of the American Physical Therapy Association recommended TUAG as a measure of balance, although with caution due to the lack of research into its measurement properties within the cancer population (Huang et al. 2015). Despite this, a separate committee of the Oncology Section of the American Physical Therapy Association (Fisher et al. 2015) highly recommended TUAG to be used as a measure of functional mobility. This high recommendation was based mainly on studies conducted on older adults to investigate age-related changes in functional mobility.

#### *5.3.1.3 Visual Analogue and Numerical Rating Scales*

Visual analogue scales (VAS) are often used in healthcare to quantify people's subjective health experience (Feng et al. 2014). VAS usually consists of a 100 mm straight line with 2 markers at each end, referring to the two extremes of the phenomena measured. People are asked to mark the line based on their symptom severity and the distance from the origin is measured with a ruler to mm accuracy. However, it is important to note that different versions of VAS are available (Jensen and Karoly 2001). Anchor words, such as mild and moderate, are often placed between the two extreme ends to demonstrate different levels of symptom severity. Similarly, symbols, such as faces reflecting different emotions related to symptom severity, can be added to the line to guide people with marking the line where it is the most representative of their symptom experience. Jensen and Karoly (2001) refer to this type of VAS as Graphic Rating Scale (GRS).

Additional anchor numbers can be added to the VAS line at every 10 mm between the two extreme ends. However, this type of modification is not always considered as VAS (Nguyen and Fabrigar 2018). Nguyen and Fabrigar (2018) state that with a numbered line people often chose whole numbers on the scale, instead of a place on the line that best describes their experience. This resembles a numeric rating scale (NRS). NRS is a list of numbers ranging from 0 to 10 (11-point scale), 0 to 20 (21-point scale) and 0 to 100 (101-point scale). People can choose the number that represents their current condition (Jensen and Karoly 2001). NRS can be used verbally or as a written checkbox questionnaire.

The combination of these scales, their understanding and taxonomy can lead to potential bias in research. Van der Molen (1995) found that comparison could not be made between studies investigating the measurement properties of VAS used in dyspnoea, because in each study a different version was used. Caraceni et al. (2005) support this, as they found 4

different versions of VAS in their literature review on pain assessment. Some of these scales were similar to NRS but titled as VAS. Moreover, Ambrosino and Scano (2004) consider numbered lines as a VAS in the assessment of dyspnoea.

To avoid bias and aid transparency, Caraceni et al. (2005) advise clarity in reporting the VAS version used to help choosing the right measures for research and clinical purposes. Moreover, Nguyen and Fabrigar (2018) advised that the measurement properties of NRS and VAS should be investigated as separate measures.

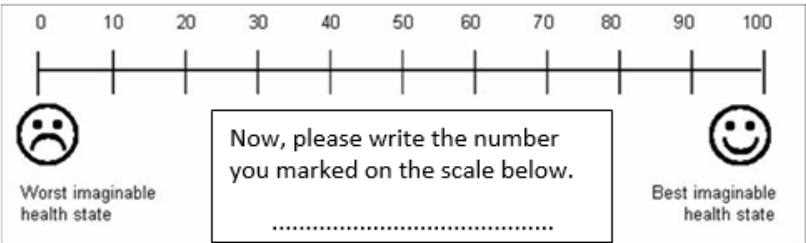
The Willow Therapy Team service used subjective scales to measure quality of life, pain and dyspnoea. These scales were a combination of VAS and NRS, a line with numbers at every 10 mm. The numbering resembled an NRS, but the line format allowed people to score between numbers. Following the recommendations of Caraceni et al. (2005) and Nguyen and Fabrigar (2018) in this thesis, the three scales used by the Willow Therapy Team are described in detail. The measurement properties of both VAS and NRS are discussed if evidence was available in the cancer population.

### **Quality of Life scale**

As part of their data collection, the Willow Therapy Team asks people affected by cancer to provide a subjective judgement on their own health and quality of life. Patients can rate their overall quality of life from 0 to 100 on a horizontal scale (Figure 5). Zero is the worst and 100 is the best health state imaginable.

Figure 5 Quality of life scale used by the Willow Therapy Team

**We would like to know how good or bad your health is TODAY.**  
**This scale is numbered from 0 to 100.**  
**Mark an X on the scale to indicate how your health is TODAY.**

0	10	20	30	40	50	60	70	80	90	100
										
Worst imaginable health state			Now, please write the number you marked on the scale below. .....					Best imaginable health state		

Horizontal visual analogue scales (VAS) are widely used in healthcare, as they are simple, easy to use measures. Often used in rating pain, horizontal VAS has also been found to be

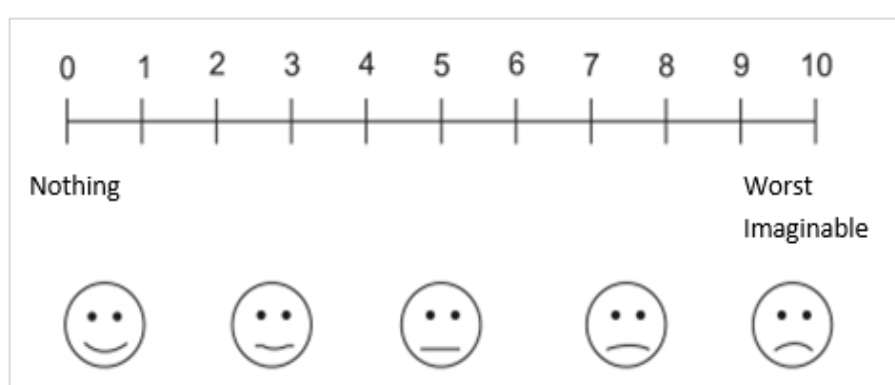
valid and reliable in measuring quality of life. De Boer et al. (2004) established the convergent validity, test-retest reliability and MCID of a horizontal quality of life VAS in oesophageal adenocarcinoma patients before and after surgical intervention. De Boer et al. (2004) used a 100 mm long horizontal scale ranging from 0 to 100. Test-retest reliability of the quality of life VAS was found good with an ICC score of 0.87 within 48 adenocarcinoma patients (De Boer et al. 2004).

Quality of life VAS was found to have good convergent validity with subscales of the Medical Outcomes Study Short Form-20 (MOS SF-20) ( $n=83$ ;  $r=0.63-0.67$ ) and the Rotterdam Symptom Check-List (RSCL) ( $n=83$ ;  $r=0.64$ ), outcome measures often used in the cancer population (De Boer et al. 2004). MCID of quality of life VAS was given as minimally important improvement (score of -3.3) and minimally important deterioration (score of -24.9) (De Boer et al. 2004).

### **Pain intensity measure**

The Willow Therapy Team used a 10 cm long line, ranging from 0 to 10 to measure pain intensity related to cancer. On the scale, 0 referred to no pain and 10 meant worst imaginable. Each centimetre on the scale was numbered to indicate pain intensity. Symbols depicting emotions related to pain severity were also added to the scale. The measure used by the Willow Therapy Team can be seen in Figure 6.

Figure 6 Scale used by the Willow Therapy Team to measure pain



The Pain VAS has been found to be reliable and valid measures of pain. Jensen (2003) found that the average correlation coefficient of Pain VAS was 0.80 across 4 studies, indicating good test-retest reliability in the adult cancer population. Jensen (2003) also investigated the validity of Pain VAS across several studies. Jensen's (2003) findings indicate that Pain

VAS strongly correlates ( $r>0.50$ ) with other pain measures, such as verbal rating scales (VRS), implying good convergent validity within the cancer population.

The NRS has also been found reliable and valid within the cancer population across numerous studies (Harrington et al. 2014; Hjermstad et al. 2011). Paice and Cohen (1997) found good convergent validity of NRS compared to VAS in a group of people with different cancer diagnoses ( $n=50$ ;  $r_s=0.847$ ;  $p<0.001$ ). The NRS used was an 11-point scale ranging from 0 to 10, while the VAS was a 10 cm line with 2 anchor descriptors of no pain and worst imaginable (Paice and Cohen 1997). Moreover, Paice and Cohen (1997) investigated participants preference for each measure. Results showed that 50% of people taking part in the study preferred NRS over VAS or VRS. A possible explanation for this was that NRS had been used more frequently in clinical settings. Participants could have already used it at hospital or doctor visits; thus, preferred NRS, because it was a familiar measure for them. The completion of VAS was also found difficult for some, as 20% of participants were unable to use the measure. However, every participant was able to use NRS and give valid responses (Paice and Cohen 1997).

These findings are supported by Rodriguez et al. (2004) who investigated the correlation and patient preference of NRS and VAS in older head and neck cancer patients. There was a strong correlation between NRS and VAS ( $n=35$ ;  $r=0.75$ ;  $p=0.0001$ ), indicating that the two measures were examining pain intensity in a similar way. The NRS used was an 11-point anchored line similar to Figure 6. VAS was a 10 cm line with two end point anchors. 57.14% of participants preferred NRS over VAS and the faces pain scale (Rodriguez et al. 2004). Furthermore, higher response variance related to education level was seen in VAS than in NRS, indicating that NRS might be an easier to use measure (Rodriguez et al. 2004).

In addition to demonstrating the measurement properties of the pain intensity measure used by the Willow Therapy Team, it is important to describe how it was used. The pain intensity responses recorded in the database of the Willow Therapy Team are an average of two pain intensity scores. Patients were asked to describe the pain that they felt at the time of the assessment and the pain they had felt at its worst. To describe the worst pain, professionals had to rely on patient's ability to accurately recall pain. Jensen et al. (2012) found that recall VAS scores strongly correlated with present VAS scores ( $n=52$ ;  $r=0.65-0.79$ ;  $p<0.001$ ), indicating high accuracy of patient's ability to remember pain intensity. Moreover, Jensen et al. (2012) calculated "characteristic pain", which is the mean of least

pain, worst pain and average pain. Recall “characteristic pain” and actual “characteristic pain” had a strong correlation with each other ( $n=52$ ;  $r=0.78-0.84$ ;  $p<0.001$ ), implying the precision of patients’ memory for different levels of pain (Jensen et al. 2012). These findings can support the use of average recall pain scores used by the Willow Therapy Team.

In summary, both VAS and NRS have been found reliable and valid measures. In addition, VAS and NRS were highly recommended in the use of cancer related pain by the EDGE Task Force (Harrington et al. 2014; Harrington et al. 2018). Both the breast cancer specific Task Force (Harrington et al. 2014) and the overall Oncology Section EDGE Task Force regarded VAS and NRS as useful measures. However, people might prefer measures that resemble NRS to VAS (Paice and Cohen 1997; Rodriguez et al. 2004), which explains why the Willow Therapy Team used a measure that is more similar to an NRS.

### **Shortness of Breath (SOB)**

Dyspnoea is a common symptom in advanced cancer. It can affect 50-70% of all cancer patients and 90% of lung cancer patients (Thomas et al. 2011), altering their quality of life. Therefore, using a measure to monitor people’s dyspnoea can be useful in cancer rehabilitation, particularly as occupational and physiotherapists can offer respiratory training, equipment and aids (Kloke et al. 2015). The Willow Therapy Team used the same scale as in pain assessment, illustrated in Figure 6 to measure dyspnoea. Similar to the method used in pain assessment, they calculated the average of the worst breathlessness experienced and breathlessness during initial assessment. In this section the psychometric properties of both VAS and NRS is discussed in the context of measuring breathlessness, as the scale displayed in Figure 6 is a combination of those measures.

The measurement properties of VAS have been investigated in various cardiorespiratory diseases (American Thoracic Society 1999; Gift et al. 1998). VAS has been recommended as a unidimensional tool to measure severity of breathlessness in a clinical setting among people with advanced disease (Bausewein et al. 2008). However, in the cancer population the properties of VAS have been rarely investigated. Dudgeon et al. (2001) compared a VRS to a 100 mm long VAS, to establish concurrent validity. There was an extremely strong correlation between VAS and VRS ( $n=923$ ;  $r=0.97$ ;  $p<0.0001$ ), indicating that the two measures can detect problems with breathlessness in a similar way.

The National Cancer Research Institute (NCRI) Palliative Care Breathlessness Subgroup advised the use of NRS as a measure of breathlessness severity and recommended it as a scale to investigate change in symptoms (Dorman et al. 2009). NRS has been found to strongly correlate with VAS in chronic obstructive pulmonary disease (COPD) patients ( $n=68-120$ ;  $r=0.56-0.82$ , respectively), suggesting good concurrent validity. This could imply that the two scales measure the same element of health. However, concurrent validity refers to the existence of a gold standard measure. Bausewein et al. (2008) found that in measuring dyspnoea there is no one instrument that can be considered as a gold standard. Therefore, Dorman et al.'s (2009) findings should be interpreted with caution. Similarly, the European Oncology Nursing Society (EONS) (2012) stated that no one tool could measure all aspects of dyspnoea. The choice of outcome measure should depend on ease of use, response burden and what aspect of dyspnoea is to be assessed. NRS is among the tools recommended by EONS (2012).

VAS and NRS might seem useful tools to measure the severity of dyspnoea, although there is a lack of research into the measurement properties of both instruments in the cancer population. Regardless, both NCRI and EONS recommend the use of NRS, and this measure has been found easier to use and preferred by patients in pain assessment. Simple measures can be useful in time-constrained clinical services, making a measure that is similar to NRS desirable for the Willow Therapy Team.

### 5.3.2 Generating operational definitions for variables

After introducing the outcome measures and data collected by the Willow Therapy Team, operational definitions were created to describe what each variable means in the secondary analysis. Operational definition is the clear, detailed definition of the variables used and how they are measured in the given study (Cheng and Phillips 2014). The operational definitions of the variables used in this thesis can be seen in Appendix 8. This step is necessary to provide transparency and help the repeatability of the analysis (Cheng and Phillips 2014). In the next section the handling of the database and the statistical analysis methods are described in more detail.

## 5.4 Data handling and statistical analysis

The anonymised database was received in three separate files. Two files contained patient data collected in 2014 and 2015. The third file consisted of data collected in 2016 and 2017.

Before merging the databases for analysis, the uniformity of categorical data, codes, and the interpretation of outcome measures were checked. This step was necessary to ensure consistency in the findings of the analysis. In cases where uniformity of the data was questionable between files, the Willow Therapy Team was contacted for clarification.

It was expected that duplicate cases might appear, due to data being collected into three separate Microsoft Excel files. After merging the data files, the database was scanned for duplicate cases. To spot possible duplicates the assessment date was used. It was anticipated that cases with the same assessment data might belong to the same person. Unique identifier numbers could not be used, as the same person could have had three different identifiers due to the anonymisation process of the three separate Excel files. Each case with same assessment dates was checked to ensure it belonged to a different person. Cancer type, gender and outcome measure scores had to be identical to declare a duplicate case. Only one of the duplicate cases was kept in the database to reduce bias.

Following the removal of duplicate cases, the whole database was imported to International Business Machines (IBM) Statistical Package for the Social Sciences (SPSS) version 25 application. All statistical analysis was performed in SPSS. The next step was the application of design variables and multi-stage sampling. The database was collected throughout 4 years. In addition, some patients attended several rehabilitation episodes. Therefore, the data was divided into 4 years and 9 to 12 episodes for analysis. This was necessary to follow changes in the outcome measures over the years and different time periods. Furthermore, breaking the data into separate years helped highlighting variations in patient uptake and service attendance overtime.

Following the application of sampling strategies, cross-tabulations, frequency tables and graphs were constructed. Descriptive statistics were calculated for continuous variables. This was necessary to explore categorical data, spot outliers in continuous variables, examine missing values and check normality for inferential statistics.

#### 5.4.1 Exploring categorical data

Categorical variables, including episodes, gender, diagnosis, and scheme are presented in graphs and figures. Bar charts are the preferred visual methods to represent quantities (Streit and Gehlenborg 2014). Therefore, it was chosen to visualise the number of cases per

episodes, and the change in cancer diagnoses over the years. Gender was also displayed to follow changes in patient uptake.

Visual presentation of data was chosen for the initial analysis of categorical data, because graphical methods enable the presentation of big samples in a compact, yet coherent way (Tufté 2001). The Willow Therapy Team database contained 4 years of patient data with over 1000 records. Therefore, a simple but all-encompassing display was necessary. Another significant aspect of graphical methods is that charts and graphs can reveal multiple levels of detail and fine structures providing an overview of the bigger picture in the data that otherwise might not be possible (Tufté 2001). In this secondary analysis, charts and graphs enabled the presentation and comparison of several years and episodes through several categorical variables.

In cases, where the analysis of bar charts indicated differences in patient uptake which could not be explained by the data, consultations were arranged with the Willow Therapy Team. The aim of these consultations was to explore any change in staff or service provision that could possibly explain discrepancies in the data. The findings from these consultations are discussed in chapter 8.

#### 5.4.2 Outliers

Boxplots and descriptive statistics, such as range were used to identify outliers, such as data entry errors. Data was considered entry error if it was out of the score range appropriate for the outcome measure. To deal with data entry errors, Pallant (2016) suggests the deletion of these values to avoid skewed data if the original paperwork is not available. Therefore, data entry errors were deleted and flagged as missing values in cases where the original therapy files were not available for the Willow Therapy Team.

Data entry errors the service could retrieve the original paperwork for were replaced following consultation with the Willow Therapy Team. Only the Willow Therapy Team had access to the original paperwork. They communicated the replaced values with the anonymised unique numbers allocated to patients to ensure confidentiality.

Outliers that were confirmed not to be data entry errors were kept in the analysis to highlight the natural variability in the population (Ghosh and Vogt 2012). Continuous data containing outliers were analysed with non-parametric tests, as unusual values lead to



skewed or heavy tailed distributions (Kitchen 2009; Ghosh and Vogt 2012). Non-parametric tests are useful alternatives to parametric tests when the assumption of normal distribution is violated (Kitchen 2009).

#### 5.4.3 Handling missing data

Missing data is any unavailable cases or values that would be relevant for analysis (Ware et al. 2012). Handling missing data is important, as the pattern of missingness can bias the findings of data analysis. Missing data can be divided into three categories depending on the mechanism that causes it: missing completely at random (MCAR), missing at random (MAR), and missing not at random (Rubin 1976; Zhou et al. 2014). MCAR refers to a pattern of missingness, in which the observed population values are identical to the missing population values (Rubin 1976). In addition, the missingness of data is unrelated to any predictor variables investigated. Therefore, this type of data could represent a random sample of the population, which means it can give unbiased results even when missing data is deleted. However, the reduced sample size due to data deletion can lead to decreased statistical power.

MAR means that the missingness of the data is not fully identical between observed values and missing cases. It might depend on a predictor variable. Therefore, the available data is not necessarily true representation of the whole population under investigation (Rubin 1976; Zhou et al. 2014). Missing not at random (MNAR) is any dataset in which the observed values and missing cases represent different populations. Missing values are dependent on observed and unobserved variables (Zhou et al. 2014).

Before any decision is made on what analytic methods should be used to handle missing data, the mechanism of missingness needs to be explored. There are different techniques available to examine the missing data pattern (Tshering et al. 2013; Jamshidian and Yuan 2014). In this study, Dixon's (1992) group comparison method was used. This method involves the use of independent t-tests to compare cases with and without missing data.

In this secondary analysis, cases were divided into two groups based on missing post rehabilitation data in each variable. Then the pre rehabilitation assessment scores were compared. Independent t-test was used if the assumption of normality was not violated within the two groups. In case of non-normal data Mann-Whitney U test, the non-parametric equivalent of independent t-test, was used for comparison.

Effect size ( $r$ ) was calculated for each test, as the probability value ( $p$ ) only indicates if the null hypothesis is rejected or retained (Maher et al. 2013). Effect size can give information about the magnitude of difference. It is advisable to report both  $p$  values and effect sizes, as  $p$  can be influenced by sample size. The bigger the sample size, the more likely it is to find a significant difference between groups (Maher et al. 2013), even if it is not a clinically important effect.

Independent  $t$ -test or Mann-Whitney  $U$  test comparison was repeated for each outcome measure, in each year for every episode. Therefore, there was missing variable comparison available for quality of life, pain and SOB scales, FACIT-F, and TUAG. Significant difference ( $p < 0.05$ ) between pre rehabilitation values of people with available and missing post rehabilitation data indicated that the data was not MCAR (Nicholson et al. 2015).

After completing Dixon's (1992) method, data was further investigated to try and understand what could have influenced the missingness of the data. Chi square test was used to investigate associations between post rehabilitation variables and discharge codes. This was necessary to identify possible observed variables that could explain the missing data pattern. Chi square has been found to be trustworthy to investigate the pattern of missingness (Nicholson et al. 2015). To get valid Chi square test results, expected counts should not be less than 5 in more than 20% of the contingency table. With cases, in which the assumption of expected counts was violated, Fisher's exact test was reported. Fisher's exact test is an alternative to Chi square, that is not limited by the expected counts (Field 2018).

After identifying the amount and pattern of missing values, a data handling method was chosen. Several techniques are available to deal with missing data; complete-case analysis, imputation techniques, weighting or model-based methods (Ware et al. 2012). However, these methods can all contribute to biased results if the data is MNAR or when there are too many missing values in the dataset (Bennett 2001; Sterne et al. 2009; Jakobsen et al. 2017). Small amount of missing data, approximately about 5% of the whole dataset, can be removed without bias (Schafer 1999). However, datasets with more than 40% of missing values can only be used to generate new hypotheses (Jakobsen et al. 2017).

In the Willow Therapy Team database there was a substantial amount of missing values (for example 47.6% - 95.1% in 2014 dependent on outcome measures) in continuous variables.

Jakobsen et al. (2017) suggested that in case of high levels of missing values, complete-case analysis should be conducted, and the limitations of the study must be discussed in detail. Therefore, in this secondary analysis, complete-case analysis was conducted. To comply with this method Sterne et al.'s (2009) missing data reporting guidelines were applied. Based on Sterne et al. (2009) the amount of missing data, suspected pattern of missingness and possible reasons for unavailable values are discussed in chapter 7.

#### 5.4.4 Checking normality

To ensure the right type of statistical analysis test was used to compare pre- and post-rehabilitation results of outcome measures, normality of the data was examined. Histograms were checked initially to spot deviations from normal distribution (Field 2018). The Kolmogorov-Smirnov test was calculated to determine if deviation from normal distribution was significant. This test was interpreted with caution, as with an increasing sample size the test is more likely to become significant even if the data is normally distributed (Field 2018).

To complement the Kolmogorov-Smirnov test and the histogram analysis, skewness and excess kurtosis were also checked. Skewness and excess kurtosis are measures of distribution shape (Field 2018). Skewness represents distribution asymmetry, while kurtosis refers to the “peakedness” of the data (Kim 2013). The closer skewness and excess kurtosis values are to 0 the more likely it is that the distribution is normal. To determine if skewness and excess kurtosis significantly differ from normal distribution, z-scores were calculated. Z-score is a value represented in standard deviation units (Field 2018). Z-score was calculated from skewness and excess kurtosis based on the following formula:  $Z_s = \frac{\text{skewness}}{SE_{\text{skewness}}}$  and  $Z_K = \frac{\text{kurtosis}}{SE_{\text{kurtosis}}}$ . SE refers to the standard error of skewness and excess kurtosis. A z-score over 1.96 suggests non-normal distribution. However, similarly to Kolmogorov-Smirnov test, z-scores can be influenced by sample size. Therefore, Kim (2013) suggested an interpretation and use of z-score that could help avoid false distribution claims (Table 9). This interpretation was used in the secondary analysis to choose between parametric and non-parametric statistical analysis tests. Histograms, Kolmogorov-Smirnov test and z-score analysis were performed for each year, episode and outcome measure pre- and post-rehabilitation.

Table 9 Interpretation and use of z-scores to spot normality in different sample sizes (Kim 2013)

<b>Sample size</b>	<b>Z-score cut off</b>
<i>N</i> <50	$Z_s$ or $Z_k < 1.96 \rightarrow$ normal distribution
50< <i>N</i> <300	$Z_s$ or $Z_k < 3.29 \rightarrow$ normal distribution
<i>N</i> >300	Use histograms and the absolute value of skewness and kurtosis to spot normality

*Key: N=sample size*

#### 5.4.5 Inferential statistics

Complete case analysis of each continuous variable was performed to compare people's health outcomes pre- and post-rehabilitation for every year and episode. Pre and post rehabilitation data were compared for each outcome measure separately. Paired t-test was used when the datasets were normally distributed (Field 2018). Wilcoxon signed-rank test was chosen in cases where data was not normally distributed (Field 2018). Results were considered significant if p value was smaller than 0.05 ( $p < 0.05$ ). Mean, standard deviation, and median were reported for each outcome measure. Reporting median was necessary, particularly with data that was not normally distributed. Median is a more useful measure of central tendency in non-normally distributed data, as it is less affected by skewness than the mean.

Table 10 Interpretation of the effect size (Cohen 1988)

<b>Correlation coefficient</b>	<b>Effect size</b>
$0.1 < r$	small
$0.3 < r$	medium
$0.5 < r$	large

In addition, effect size  $r$  was reported. Effect size  $r$  is a flexible value that can be calculated for parametric and non-parametric tests (McGrath and Meyer 2006), making it valuable for this secondary analysis where data distribution in different years and episodes was not always normal. However,  $r$  calculations differ between parametric and non-parametric tests (Rosenthal 1991). The following formulas were used to calculate  $r$  effect size, as this cannot be performed in SPSS:  $r = \frac{t^2}{t^2 + df}$  for parametric tests and  $r = \frac{z}{\sqrt{N}}$  for non-parametric tests. The value of  $t$  and  $z$  can be extracted from the SPSS outputs of paired t-test and Wilcoxon signed-rank test. To interpret  $r$ , the guidance of Cohen (1988) was used (Table 10).

## 5.5 Chapter conclusion

In this Chapter secondary analysis and the way it was conducted in this thesis were discussed in detail. Quantitative methods are often used in realist evaluation to build and test theories (Westhorp 2011; Pawson and Tilley 2001). As mentioned earlier in the Chapter, secondary analysis of the Willow Therapy Team could provide information on service population, uptake, and potential impact. This data contributes to the understanding of the potential outcomes. Therefore, results of this secondary analysis were used in conjunction with qualitative data to support or refute initial programme theories. The next chapter describes how qualitative data was gathered and analysed for this thesis.

## Chapter 6: Qualitative interview methods

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As mentioned in the previous chapters of this thesis, to explore further how cancer rehabilitation services work, there is a need for in-depth investigation. Qualitative research can provide a deeper understanding of people's experiences of cancer rehabilitation and for whom it works, in what circumstances and how. This chapter aims to introduce the methods used to explore cancer rehabilitation from the perspectives of cancer rehabilitation healthcare professionals and people affected by cancer. In this chapter firstly the sample population, size and recruitment process are described followed by a brief summary of ethical considerations. Then the data collection and analytic procedures are presented, closing with the procedures applied to ensure rigour.

### 6.1 Participants

To investigate how cancer rehabilitation works in South Wales, cancer specialist healthcare professionals and people affected by cancer were recruited from the Willow and Fern Therapy Teams. Participants were recruited for this PhD study between March 2018 and May 2019. Purposive sampling was chosen, because this method enables researchers to recruit specific participants with certain characteristics who might be able to answer the research questions (Robson 2016). Furthermore, in realist evaluation purposive sampling enables theory testing (Manzano 2016).

#### 6.1.1 Sample size

Recruiting at least 20 participants is advisable to provide credibility to the data (Manzano 2016). Accordingly, in this study phase I aimed to interview up to 20 healthcare professionals and up to 20 people affected by cancer. However, realist evaluation is concerned with what works and for whom and the quality of interviews is more important in realist evaluation and qualitative research than the number of participants (Manzano 2016). Thus, when sufficient data, or saturation, is achieved, data collection can stop (Saunders et al. 2018). In this PhD study, data processing commenced after each individual interview in the form of transcription, followed by data analysis determining saturation.

### 6.1.2 Recruitment of healthcare professionals

Recruitment of healthcare professionals was supported by gatekeepers at the Willow and Fern Therapy Teams. The gatekeepers promoted the study, disseminating invitation letters (Appendix 11) and participant information sheets (Appendix 12), and organising team meetings where I could present the purpose of the study. If they were interested in participating in the study, healthcare professionals could contact me directly through the details on the invitation letters or after the presentations, thereby ensuring their privacy and confidentiality. After the initial contact, healthcare professionals were prompted to get in touch if they had any further questions. I followed up people who indicated interest in the study and, if they were still interested and met the eligibility criteria, a date, time, and place was agreed for an interview. Inclusion and exclusion criteria are presented in Table 11. Written informed consent was obtained from the participants on the day of the interview. Consent form is presented in Appendix 13.

Table 11 Inclusion and exclusion criteria for qualitative interviews

Healthcare professionals		People affected by cancer	
Inclusion criteria	Exclusion criteria	Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> <li>Over the age of 18 years</li> <li>Holding appropriate professional qualification and registration</li> <li>At least 1 year experience in working with cancer patients</li> </ul>	<ul style="list-style-type: none"> <li>Under the age of 18 years</li> <li>Students</li> <li>Lack of training or professional registration</li> <li>Less than 1 year experience in working with cancer patients</li> </ul>	<ul style="list-style-type: none"> <li>Over the age of 18 years</li> <li>Have been taking part in cancer rehabilitation provided by the two study sites</li> <li>Have the capacity to consent and participate</li> <li>Understand and able to communicate in English</li> </ul>	<ul style="list-style-type: none"> <li>Under the age of 18 years</li> <li>Have not received rehabilitation from any of the services</li> <li>Do not have the capacity to consent and participate</li> <li>Cannot communicate in the medium of English</li> </ul>
Every potential participant must be willing to take part.			

### 6.1.3 Recruitment of people affected by cancer

The recruitment of people affected by cancer was supported by healthcare professionals working at the Willow and Fern Therapy Teams. Healthcare professionals distributed invitation letters (Appendix 14), response slips (Appendix 15), and pre-paid envelopes to eligible people at their first rehabilitation appointment or assessment for a new rehabilitation episode. Inclusion and exclusion criteria are presented in Table 11 above.

People affected by cancer were asked to read the invitation letter and return the response slip in the pre-paid envelopes to me if they were interested in the study. This way people affected by cancer did not have to let the rehabilitation team know about their interest in the study and thus they could keep their response confidential. Moreover, people affected by cancer could contact me directly on the contact details stated on the invitation letter. Only those people affected by cancer were followed up who returned the response slip or contacted me on the details printed on the invitation letter.

To record response rate, the envelopes were numbered, and healthcare professionals were asked to record the number and date on a tally sheet when the response slips were given to people affected by cancer. People could refuse to accept the response slip, which had to be written on the tally sheet.

Within the invitation letter, people affected by cancer were offered a choice. They could decide if they would like to take part in the individual, semi-structured interviews or a questionnaire study which is not included in this thesis, and not discussed any further here. When people returned the response slip or contacted me directly, a detailed information sheet was sent to them (Appendix 16). When people opted for individual semi-structured interviews, I arranged a date for a meeting after the participant's last rehabilitation appointment. Written informed consent was obtained on the day of the interview. The consent form is presented in Appendix 17.

#### 6.1.4 Ethical considerations

During participant recruitment of healthcare professionals and people affected by cancer, ethical issues must be considered. Information, confidentiality, privacy, and choice are important principles of all healthcare research and must be respected throughout every stage of the study (NHS HRA 2017). Information is important, so participants can make informed decisions about their involvement in research. During recruitment for this research, invitation letters and information sheets were given to all potential participants. Having agreed to participate in an interview both healthcare professionals and people affected by cancer were offered at least 48 hours to consider the information before the interview and ask questions. Every participant was assured that participating in interviews was voluntary and they could withdraw from the study at any point without this affecting their work (healthcare professionals) and care (people affected by cancer).



Confidentiality was considered to keep participation anonymous. Healthcare professionals and people affected by cancer could contact me directly after receiving the invitation letters, thereby ensuring their colleagues or therapists did not learn about their participation in the study. In addition, all data was anonymised, and no identifiable data was used during analysis and dissemination of findings.

Participating in research can have disadvantages that need to be considered by the researcher and mitigating actions should be planned to reduce risks of physical or emotional damage. This was a qualitative interview study which gave a chance to people to talk about their illness and cancer treatment experiences. There was no physical risk associated with taking part in the study, although people's illness experiences could be emotional or traumatic. It was considered that asking participants to talk about their cancer diagnosis and rehabilitation might upset them. People were informed about this risk in the participant information sheets and they had the option to withdraw from the study. At the planning of the study, it was decided if a participant had got distressed, the interview would be stopped and resumed only if the participant was happy to continue. If the participant decided not to continue with the interview and reschedule, another suitable date would be arranged. The participant would be comforted and if a participant disclosed a need for longer term help or support, the number of the Macmillan Helpline or the contact details of their therapy team would be provided. Moreover, participants were advised that they could bring a companion with them. Companions during the interview could provide emotional support if needed and support the participants during the interview. During the course of the interviews only one person became emotional while talking about her experiences. She was comforted, asked if she required any further help and decided to continue with the interview.

The disclosure of malpractice by any healthcare professional was another ethical issue that had to be considered. As a Health and Care Professions Council (HCPC) member and a registered physiotherapist, it was my obligation to report any practices that put people's health in danger. If that had happened, I would have stopped the audio recordings and not included the data in the study. Based on the All Wales Raising Concerns (Whistleblowing) Policy (2013), I would have reported the issue to the study gatekeepers without disclosing the participant's name. No malpractice was disclosed while interviewing.

To familiarise myself with the ethical scientific practices and to adhere to research requirements, I attended the Good Clinical Practice (GCP) introductory course. My GCP introductory and refresher certificate is presented in Appendices 20 and 21. Ethical approval was obtained from London South-East Research Ethics Committee (17/LO/2123) (Appendices 4 and 5). In addition, the Research and Development (R&D) Department of both hospitals, in which the Willow and Fern therapy teams are located, reviewed this PhD study and provided a Letter of Access (Appendices 6 and 7).

## 6.2 Procedures

Individual, face-to-face, digitally audio recorded semi-structured interviews were conducted with participants. The semi-structured interview method was chosen, as it enables the use of a loose topic guide to focus the conversation on the research objectives of the research (Gerrish and Lacey 2010). Meanwhile semi-structured interviews leave enough space to discuss other subjects that are not covered in the topic guide but have relevance to the participants' experiences and to the research (Gerrish and Lacey 2010). This flexibility was particularly important as in realist evaluation it is important to test new potential programme theories that emerge during the interviews (Manzano 2016). Interview topic guides with open-ended questions were developed. Separate guides with similar main research questions were made for healthcare professionals (Appendix 9) and for people affected by cancer (Appendix 10) to enable the representation of different perspectives. The literature review and consultation with experts in the project Steering group informed the development of the interview guides.

Individualised face-to-face interviews were chosen over focus groups, as cancer can be a difficult topic to talk about for some people (Emslie et al. 2007). It was anticipated that people affected by cancer may have not wanted to talk about their diagnosis and rehabilitation needs in front of peers, particularly if their needs were of sensitive nature. As mentioned above, people affected by cancer, who wished to have a companion with them, were supported to bring a family member, a friend, or a carer along. The presence of a companion has been found beneficial as they can also provide further depth to the interview by adding information that the person affected by cancer might have forgotten (Morris 2001). Companions were offered information sheets (Appendix 18) and time to read the information sheet and consider participation. Companions who were willing to

participate in the interviews gave written informed consent. An example of the companion consent form is in Appendix 19.

Regarding healthcare professionals, as participants were recruited from different disciplines, such as dietetics, physiotherapy, occupational and speech and language therapy, individual interviews allowed them to discuss issues specific to their profession.

All interviews were conducted in quiet, comfortable places in accordance with participants' preferences. Indeed, participants were given the option to decide the location and time of the interview. All participants were given a choice between their own home, the hospital where they work or receive treatment, and university facilities.

Interviews were audio recorded. At the end of the interviews, participants were asked if there was anything they felt important and would have liked to share. After the interview there was an unrecorded period of time for the participants to ask questions and talk about the interview process. Field notes were made after the interview was finished, to describe surroundings, non-verbal communication during the interviews and fresh ideas that were brought up by the participants. In addition, the construction of field notes immediately after the interviews aided my reflection on the course of the interview and my role as the interviewer.

### 6.3 Analytic approach

Reflexive thematic analysis by Braun and Clarke (2006) was broadly followed as an analytic approach to identify not just simply themes, but also contexts, mechanisms, and outcomes in the interviews. Braun and Clarke (2006) defined thematic analysis as a qualitative method, which outlines, analyses, and presents the most commonly occurring and meaningful patterns or themes in the data. They suggest that thematic analysis should be considered as a foundation of all qualitative analytic methods. As a basis of analytic methods, it is suitable for researchers who are just getting familiar with qualitative research. This was particularly important in this thesis, as I am a novice qualitative researcher. In addition, as reflexive thematic analysis does not belong to any theoretical framework, it can be used with different methodologies. However, Braun and Clarke (2006) stated that thematic analysis is usually realist if no other theoretical standpoint is made. Therefore, the analytic method's theoretical flexibility and its general realist account made it suitable for this PhD study.

Braun and Clarke (2006) developed a six-phase guideline to conduct thematic analysis (Table 12). This was broadly followed during the analysis of qualitative data in this thesis. As this PhD study is a realist evaluation, to analyse the data mainly retroductive thinking was applied to find causal relationships between codes and data extracts.

Table 12 Six-step guidance by Braun and Clarke (2006)

**Braun and Clarke (2006) Reflexive thematic analysis**

1. Familiarisation with the data (transcription, reading and re-reading of the data)
2. Generating initial codes
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes
6. Producing the report

The first phase in thematic analysis is the familiarisation with the data. Braun and Clarke (2006) advise that if possible, producing one's own transcripts is the best way to get to know the data. I therefore made the decision to transcribe the data myself. I used Soundsciber (University of Michigan) to listen and automatically rewind interviews. Transcripts were typed up verbatim in Microsoft Word. Pauses, sighs, highlights were added to the transcripts where necessary. Moreover, during transcription, notes were made on initial ideas about the data and potential codes. An excerpt of the transcription notebook can be seen in Figure 7. While producing my own transcripts and writing down my initial thoughts and ideas was time consuming, it enabled me to deeply engage with the data and discover potential causal relationships within and between interviews.

Figure 7 Excerpt from transcription notebook

perceived benefits of rehabilitation  
 - previous two patients have mentioned positive psychological effects → able to relax, able to sleep better  
 - hope to beat cancer → better mental health? → physical exercise → improved attitude?  
 - "I think he did not fully understand the question what cancer rehabilitation meant to him before [redacted] → however → referring to "anything that will make me feel better" is rehabilitation related to something that will make you feel better?  
 - "feel as if I'm coming back to life" → similar to getting back to normal? (Patient-03)  
 - mentioning a potential barrier → he could have not done rehab (hydrotherapy / gym) if he had not give up his work → it could explain why the majority of patients is retired → if you work there appointments are not flexible enough  
 - concentrating on rehab fully could result in him getting back to work → giving yourself time to heal can result in better outcomes  
 - not working and having time for rehab is a facilitator  
 - some people are more closed → need more persuasion → professionals maybe need to focus on getting these people understand that rehab is good for them →

The second phase was the development of initial codes. Codes outline a part of the data of interest to the researcher or the research question. I coded all interviews line-by-line on transcript hard copies. Initial codes than were discussed with the supervisory team to compare their coding to mine.

Once all interviews were coded, I started mapping the codes onto the IPTs to test them. During the third phase, related codes were linked together to identify potential contexts, mechanisms, and outcomes. I typed up potentially related codes into a separate Microsoft Excel document to enable mapping them onto the IPTs. Causal relationships between codes and data extracts were discussed with the supervisory team. Differences between the two therapy teams and the accounts of healthcare professionals and people affected by cancer were compared after codes were generated and was considered during the refinement of new CMOs.

## 6.4 Rigour

For high quality research, qualitative data needs to be trustworthy. Trustworthiness encompasses five quality criteria that must be followed to reduce the chance of bias as much as possible (Korstjens and Moser 2018). These criteria are: credibility, transferability, dependability, confirmability, and reflexivity (Lincoln and Guba 1985, Korstjens and Moser 2018). Different methods can be used to ensure that the data is trustworthy. The different criteria and the methods used in this thesis are introduced below.

Credibility focuses on how true the research findings are. Credibility ensures that the views represented as the findings are the correct interpretations of the participants' experiences (Lincoln and Guba 1985, Korstjens and Moser 2018). To provide credibility in this thesis, methodological triangulation and negative case analysis were used. Methodological triangulation means that both qualitative and quantitative methods are used (Robson 2016). In this thesis, as part of the realist evaluation process, I used mixed methods. In the presentations of the findings, I compared and contrasted the qualitative and quantitative data to have a comprehensive insight into the outcomes of this realist evaluation. In addition, I strived for negative case analysis, which meant I was actively looking for cases that negated and contrasted the CMOs that I was building (Lincoln and Guba 1985).

Transferability refers the transferable quality of the research onto other settings and environments. Thick descriptions are the rich exploration of the setting beyond people's

experiences and behaviours (Lincoln and Guba 1985, Korstjens and Moser 2018). In this thesis, context was investigated as part of the realist inquiry. However, to ensure that context is adequately represented, the participants were introduced and described, not only in the exploration of the CMOs, but prior to it in chapter 7. Participant age, profession, diagnosis, and the rehabilitation interventions they attended were all considered beyond their experiences.

Dependability refers to the stability of the data over time. This means that findings are consistent and could be repeated by other researchers. (Lincoln and Guba 1985). External audit was used in this study to determine the dependability of the findings (Lincoln and Guba 1985, Korstjens and Moser 2018). Findings were discussed with the supervisory team to determine if my interpretation of the data was similar to others’.

Confirmability ensures that the findings of the analysis are undeniably derived from the data and not accidentally made up by the researcher (Lincoln and Guba 1985, Korstjens and Moser 2018). A clear audit trail can demonstrate the confirmability of qualitative research. In this study, I recorded my research steps and procedures in my diary to ensure the rigour of my analysis and I provided a clear description of research procedures in this chapter.

Reflexivity is a method in qualitative research that provides rigour by identifying the researcher as a member of the society. It recognises that the researchers’ background can shape their thinking and beliefs, which can influence the analysis (Gerrish and Lacey 2010). I wrote a reflective diary to explore my role in conducting and analysing interviews.

## 6.5 Conclusion

This chapter summarized the methods used in qualitative data collection and analysis for the purposes of this realist evaluation. Individualised semi-structured interviews were conducted with healthcare professionals and people affected by cancer. Thematic analysis was used to identify causal relationships and potential CMOs in the data that can support or refute the IPTs. The next chapter aims to introduce the participants who consented to take part in this PhD study and the routinely collected database following the removal of duplicate cases, outliers and handling of the missing data.

## Chapter 7: Participants and data

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This chapter aims to introduce the healthcare professionals and people affected by cancer who took part in the semi-structured interviews and describe the routine data collected by the Willow Therapy Team. Before the findings of this PhD study are presented, it is important to detail how many participants consented to take part in the qualitative interviews, what characteristics they possessed, and how long the interviews were. Then, the exploration of the routine data is presented to provide clarity on the number of cases contained in the database and what data was available for analysis.

### 7.1 Qualitative interview participants

As mentioned in chapter 4, to thoroughly investigate the mechanisms and contexts that make cancer rehabilitation work, both healthcare professionals and people affected by cancer were recruited. First, the healthcare professionals are introduced.

#### 7.1.1 Healthcare professionals recruited for qualitative interviews

The recruitment target for healthcare professional interviews was met ( $n=20$ ). Ten healthcare professionals were recruited from each of the study sites. Written informed consent was obtained from every healthcare professional prior to the interview. The professional groups represented in the interviews were therapy technicians, dietitians, physiotherapists, occupational (OTs) and speech and language therapists (SLTs). All together four technicians, four dietitians, three physiotherapists, five OTs and four SLTs were interviewed.

##### *7.1.1.1 Healthcare professionals interviewed from the Fern Therapy Team*

The professionals recruited from the Fern Therapy Team are shown in Table 13. Every interviewee had over a year experience in cancer rehabilitation and oncology. Three healthcare professionals had less than a year experience in their current role but had been working as an oncology specialist at another hospital or in other roles. Two healthcare professionals did not provide information on how many years of experience they had prior to their current role, but when asked they mentioned they had a couple of years' experience as an oncology professional. Professionals' oncology and cancer rehabilitation

experience ranged from 1 year and 3-4 months to 19 years. The majority of the healthcare professionals who consented to take part were SLTs ( $n=3$ ) and technicians ( $n=3$ ). All healthcare professionals interviewed from the Fern Therapy Team were women.

Table 13 Healthcare professionals recruited from the Fern Therapy Team

Participants	Profession	Experience in cancer rehabilitation
Professional_02	Speech and language therapist	2 years
Professional_03	Technician	1 year 3-4 months
Professional_04	Dietitian	3 years 6 months
Professional_05	Technician	4 years and 6 months
Professional_06	Physiotherapist	8 years
Professional_07	Dietitian	9 months in current role + couple of years in community cancer care
Professional_08	Technician	10 months in current role + couple of years in different oncology related roles in the same hospital
Professional_09	Speech and language therapist	5 years
Professional_12	Occupational therapist	4 years
Professional_13	Speech and language therapist	1 year 2 months in current role + 18 years in other hospitals

The SLTs mainly worked in the field of head and neck cancer and neuro-oncology, but they often picked up referrals from other cancer sites if a person had swallowing or communication difficulties. SLTs received referrals from both the inpatient ward and outpatient services, although their outpatient service uptake was dominant. In addition, SLTs attended multidisciplinary (MDT) head and neck cancer review clinics, where they saw most people affected by cancer undergoing radiotherapy.

Two of the three technicians recruited from Fern worked with OTs and physiotherapists. These technicians' roles were split, spending six months working with physiotherapists, then six months with OTs. The OT/physiotherapy technicians' role included hands on tasks on the inpatient ward and reviewing people affected by cancer who had been assessed by the OTs or the physiotherapists. In addition, they provided key help with documentation and equipment prescription for people affected by cancer. The third technician (Professional\_07) worked with the SLTs, although previously worked in different roles within the hospital. The SLT technician provided people affected by cancer with swallowing exercises, and significantly contributed to paperwork and reviewing cases.



Two dietitians were interviewed from the Fern Therapy Team. Dietitians provided nutritional support mainly for people affected by head and neck and upper gastrointestinal (GI) cancer. Dietitians saw people affected by cancer in both inpatient and outpatient settings. Dietitians attended the head and neck cancer review clinics with the SLTs for optimal MDT working. In addition, they ran drop-in clinics for anyone who had issues with weight, nutrition, and digestion, and they contributed to the fatigue management group with a session on nutrition and fatigue.

Finally, one physiotherapist and one OT were interviewed. The physiotherapist (Professional\_06) worked with a wide range of people affected by cancer who had respiratory, incontinence, mobility, or functional issues. Some of the most common cancer sites seen by her were breast, neuro-oncology, lung, and gynaecological cancer. Fern physiotherapists in general saw people with metastatic spinal cord compression (MSCC) and provided acupuncture for people who had hot flushes as a side effect of cancer treatments. People with physiotherapy needs were identified from both inpatient and the outpatient settings. In addition, physiotherapist at the Fern Therapy Team offered pilates classes.

The OT (Professional\_12) saw a wide range of people affected by cancer, similar to the physiotherapists. The OTs provided help with adapting to people's changing functional capacities with equipment and self-management techniques. People were often identified from the inpatient ward and outpatient services. OTs had a substantial role in discharging people home by assessing equipment need and prescribing the right tools, such as hospital beds and commodes. The OTs provided home visits to assess the environment and ensure that discharge to home was possible and safe. In addition, OTs provided outpatient services, such as the fatigue management group and a seating and posture service for people who had issues with sitting post treatments. At the time of the interview, the OT team was working on establishing a vocational rehabilitation service, which aims to provide support for people to learn their work rights and plan their return to work.

#### *7.1.1.2 Healthcare professionals interviewed from the Willow Therapy Team and its local hospital*

The healthcare professionals recruited from the Willow Therapy Team and its local hospital are shown in Table 14. As the Willow Therapy Team mainly employs OTs and

physiotherapists, dietitians and SLTs were recruited from the hospital in which the Willow Therapy Team is located. These dietitians and SLTs were cancer specialists who often referred people affected by cancer to the Willow Therapy Team if they identified the need for it. Recruiting dietitians and SLTs for this thesis was crucial to provide a comparable sample to the Fern Therapy Team. Moreover, even though dietitians and SLTs do not work in the Willow Therapy Team directly, these allied health professionals (AHPs) contribution to people's health and wellbeing is substantial.

Table 14 Healthcare professionals recruited from the Willow Therapy Team and its local hospital

Participants	Profession	Experience in cancer rehabilitation
Professional_01	Occupational therapist	16 years
Professional_10	Technician	7 years
Professional_11	Speech and language therapist	5 months in current role + 5 years in another hospital
Professional_14	Occupational therapist	10 years
Professional_15	Physiotherapist	5 years
Professional_16	Occupational therapist	3 years
Professional_17	Dietitian	7 months in current role + 9 years in another hospital
Professional_18	Dietitian	17 years
Professional_19	Physiotherapist	10 years
Professional_20	Occupational therapist	16 years on and off

Regarding the characteristics of the interview sample, every healthcare professionals had more than one year's experience in cancer rehabilitation. Two AHPs had less than a year experience in their current role, but they had worked as a cancer specialist at their previous workplace in another hospital. The interviewed healthcare professionals' practice experience ranged from 3 years to 17 years. Minimum experience was slightly higher than at the Fern Therapy Team, but maximum experience was somewhat lower.

All healthcare professionals interviewed were women. Most of the participants recruited from the Willow Therapy Team were OTs (n=4). The OTs worked directly for the Willow Therapy Team. In contrast with the Fern Therapy Team, where professionals picked up patients from both the inpatient ward and the outpatient services, the Willow Therapy Team divided OTs and physiotherapists to work on inpatient and outpatient wards.

The two healthcare professionals who worked in the inpatient ward and the outpatient services saw a wide range of people affected by cancer. Neither the inpatient ward, nor the outpatient service was cancer site specific. Inpatient OTs at the Willow Therapy Team

attend ward rounds with the wider MDT every morning and attended to every person with rehabilitation needs. As with services provided by the Fern Therapy Team, Professional\_20, had an active role in improving people's functional mobility and helping people adapt to cancer related physical and psychological changes. In addition, the inpatient OTs had an important role in managing home discharge, equipment prescription and providing home visits to ensure that circumstances are appropriate and safe for home discharge. The outpatient OT (Professional\_16) provided the exercise classes, such as hydrotherapy, circuits, Tai Chi, and individual therapies.

Two physiotherapist who worked for the Willow Therapy Team were interviewed. One of them worked on the inpatient ward (Professional\_19), while the other worked on the outpatient ward (Professional\_15). Physiotherapists and OTs work closely within the Willow Therapy Team and often share competencies, such as running the exercise classes. A therapy technician was also interviewed (Professional\_10). The therapy technician's role within the Willow Therapy Team included both inpatient and outpatient support and assistance with documentation.

Out of the two interviewed dietitians, Professional\_17 was a head and neck cancer specialist. She saw people affected by head and neck cancer at review clinics alongside the MDT. Professional\_17 aimed to provide outpatient nutritional support throughout and post treatment. Professional\_18 worked mostly with people affected by upper GI and lung cancer to oversee their nutritional needs throughout treatment. She mainly worked in outpatient services, often alongside the MDT in review clinics, but additionally offered individual dietetic consultations including a clinic day dedicated to a wide range of cancer sites. The SLT interviewed (Professional\_11) was a head and neck specialist providing support for people affected by cancer. The SLTs worked on both inpatient ward and the outpatient services to provide support with people's swallowing and communication.

#### *7.1.1.3 Summary of healthcare professionals recruited for qualitative interviews*

In summary, the target sample size for the healthcare professional interviews was met and a wide range of AHPs and technicians participated in the interviews providing a comprehensive picture on how cancer rehabilitation services work in South Wales. Professionals worked in both inpatient and outpatient services and covered a broad spectrum of cancer sites. All healthcare professionals interviewed met the inclusion criteria,

as their collective oncology practice experience ranged from 1 year and 3-4 months to 19 years. The next section aims to introduce the people affected by cancer who took part in the interviews

#### 7.1.2 People affected by cancer recruited for qualitative interviews

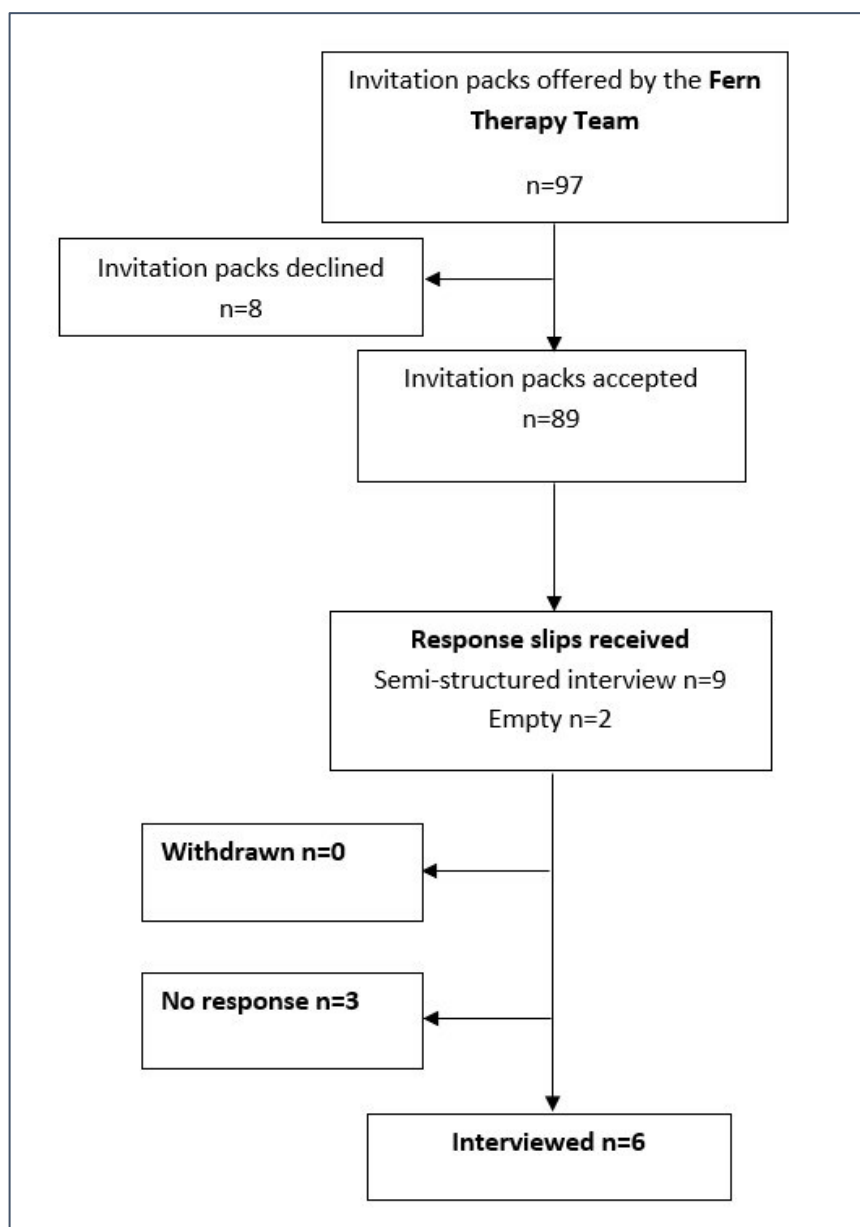
Compared to the healthcare professional sample size, recruitment of people affected by cancer did not meet the originally set sample of 20. Fifteen people affected by cancer gave written informed consent to be interviewed. However, these 15 interviews provided a rich description of people's experiences with cancer rehabilitation and similar themes in the data could be detected within and between the two therapy teams. When breaking the sample down to the two therapy teams, six people affected by cancer consented to be interviewed from Fern, and nine from Willow. The next sections detail the response rate for the invitation packs given out by the teams and the characteristics of the people who participated in the interviews.

##### 7.1.2.1 *People affected by cancer recruited by the Fern Therapy Team*

The recruitment procedures are detailed in chapter 6 of this thesis. Figure 8 below depicts the recruitment process and shows the number of people who were approached with study invitation packs, number of people who declined, response slips returned, people withdrawn or could not be contacted and the final sample size. The tally sheets indicated that healthcare professionals working for the Fern Therapy Team approached 97 people affected by cancer with invitation packs to this PhD study. Eight people declined the invitation packs, indicating no interest in the study. Out of the 89 invitation packs accepted, 11 people returned the response slips to me. Considering the invitation packs accepted and response slips returned this shows 12% response rate. As mentioned earlier in the methods section, people affected by cancer had a choice to be interviewed or take part in a questionnaire study. This response rate does not reflect the responses to the questionnaire study. Out of the 11 response slips received, 9 indicated interest in participating in semi-structured interviews. Two response slips were received empty, with no indication of interest or contact details, implying that these two people did not want to take part in the study after reading the invitation letter. Out of the nine people who were sent participant information sheet and were contacted to arrange an interview date, three people did not respond to phone calls or e-mails; therefore, I could not arrange an interview. The final

sample from the Fern Therapy Team included 6 interviews. As this chapter aims to introduce the participants, my reflections on the recruitment strategy and possible reasons for the low response rate will be discussed in chapter 11.

Figure 8 Recruitment process of people affected by cancer for semi-structured interviews from the Fern Therapy Team



The interviewees' characteristics recruited from the Fern Therapy Team are presented in Table 15. The majority of the interviewees were female (n=4) and had breast cancer (n=3). Two of the three participants with breast cancer were younger and still in employment (Participant\_21 and Participant\_37). Participant\_21 was struggling with hot flushes due to her treatments and she received acupuncture from the physiotherapy team to ease these

side effects. Participant\_37 attended the fatigue management group organised by the OTs from the Fern Therapy Team, as she was experiencing cancer-related fatigue. The third person who had breast cancer (Participant\_18) received acupuncture for her hot flushes by the physiotherapy team. One of the female participants (Participant\_39) had thyroid cancer. Participant\_39 was diagnosed with thyroid cancer 16 years before participating in the interview. However, she had annual follow-ups at the hospital where the Fern Therapy Team is located. As Participant\_39 had started experiencing swallowing difficulties in recent years, she had been in contact with the SLT at the Fern Therapy Team.

Table 15 Interviewees' characteristics who attended services of the Fern Therapy Team

Participants	Diagnosis	Gender	Age at interview (years)	Intervention	Work status
Participant_18	Breast	Female	69	Acupuncture	Retired
Participant_21	Breast	Female	37	Acupuncture	Teacher
Participant_27	Lung	Male	58	Dietitian/SLT	Retired
Participant_29	Prostate	Male	65	Fatigue management	Retired
Participant_37	Breast	Female	44	Fatigue management	Civil engineer
Participant_39	Thyroid	Female	61	SLT	Self-employed

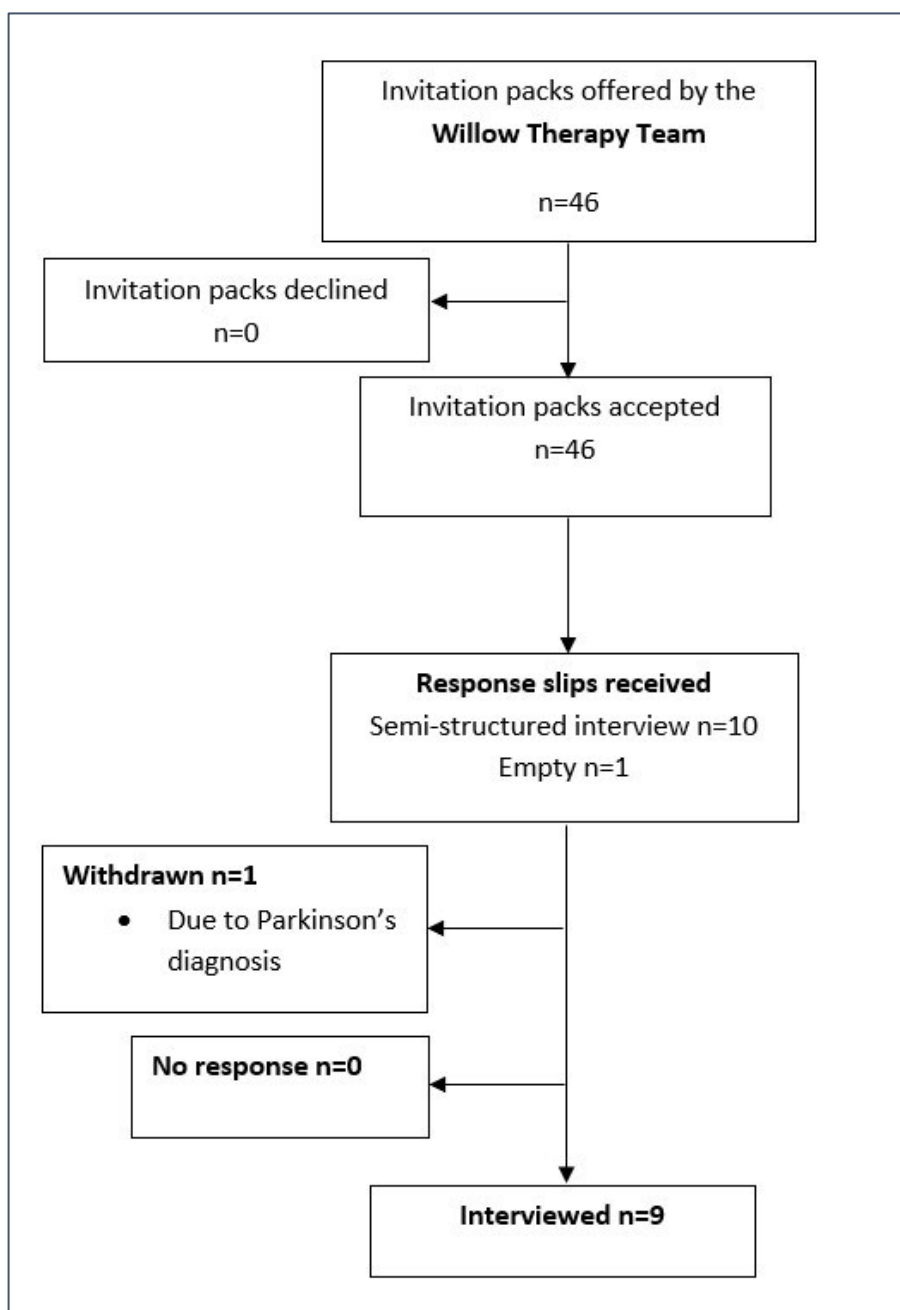
The two male interview participants had lung (Participant\_27) and prostate cancer (Participant\_29). Participant\_27 had swallowing difficulties during his inpatient stay while receiving radiotherapy, that is how he met the dietitian and the SLT. Participant\_29 experienced cancer-related fatigue and attended the fatigue management group run by the OTs of Fern. Although people were encouraged to have a companion with them for the interview if they needed support, none of the participants recruited from the Fern Therapy Team decided to have their partners or friends with them.

#### *7.1.2.2 People affected by cancer recruited by the Willow Therapy Team*

Figure 9 below shows the process how people affected by cancer were recruited by the Willow Therapy Team. Invitation packs were offered to 46 people affected by cancer. In contrast with the Fern Therapy Team, no one declined the invitation packs. Of the 46 people, 11 returned the response slips regarding semi-structured interview participation or indicating lack of interest in the project. Based on these numbers, the response rate was 24%. Of the 11 response slips, only one non-completed slip was returned, indicating no interest in the study. Ten participants were sent participant information sheets and were contacted to arrange an interview date. Interview dates were arranged with all ten people,

although one person had to withdraw due to ongoing medical investigation for Parkinson's disease. The final number of participants was nine.

Figure 9 Recruitment process of people affected by cancer for semi-structured interviews from the Willow Therapy Team



The characteristics of people affected by cancer who consented to be interviewed from the Willow Therapy Team is shown in Table 16. Unlike the sample recruited from the Fern Therapy Team, the majority of the interviewees were male ( $n=6$ ). In addition, all male participants had prostate cancer. Participants affected by cancer attended the Willow

exercise classes for various cancer related health issues. Examples include fatigue, anxiety, depression, mobility issues, weight gain and deconditioning. Three participants affected by prostate cancer learnt about the therapy team through attending education events and peer support groups at a local cancer support centre run by a third sector organisation. Participant\_09 was referred to the services by his oncologist, while Participant\_10 and Participant\_30 were unsure who referred them, but from their description it is would appear that this was their cancer nurse specialist (CNS).

Table 16 Interviewees' characteristics who attended services of the Willow Therapy Team

Participants	Diagnosis	Gender	Age at interview (years)	Intervention	Work status
Participant_01	Prostate	Male	66	Circuits	Retired
Participant_02	Colorectal	Female	63	Tai Chi	Retired
Participant_03	Breast	Female	74	Tai Chi/Circuits	Retired
Participant_09	Prostate	Male	60	Hydrotherapy/Circuits	Retired
Participant_10	Prostate	Male	70	Hydrotherapy	Retired
Participant_12	Prostate	Male	84	Hydrotherapy	Retired
Participant_16	Prostate	Male	68	Circuits	Retired
Participant_28	Breast	Female	70	Hydrotherapy/Circuits	Retired
Participant_30	Prostate	Male	78	Circuits	Retired

Out of the nine interview participants, three were female. Two of them had breast cancer and one had colorectal cancer diagnosis with gynaecological metastasis (Participant\_02). Participant\_02 sought help from the Willow Therapy Team due to deconditioning. She was referred to Willow Therapy Team through her local physiotherapy department who were unable to attend to her rehabilitation needs. Participant\_03 learnt about the Willow Therapy Team through an education event for people affected by breast cancer. She experienced deconditioning among other cancer related health issues and thought that attending Tai Chi classes would be beneficial for her. Participant\_28 had issues with the muscle strength of her right arm following her lumpectomy. The lymphoedema team was concerned for her as her right arm had visible muscle atrophy; thus, the lymphoedema professionals referred her to the Willow Therapy Team. In contrast with the Fern Therapy team, every interviewee was retired.

Three participants had their partners with them during the interviews, thus resulting in dyadic interviews. Participant\_10 and Participant\_16 came with their wives. Participant\_28



was joined by her husband during the interview. All companions supported and enriched the interviews, and no issues were observed with dominant companions.

### *7.1.2.3 Summary of people affected by cancer recruited for qualitative interviews*

In summary, people were recruited from the two cancer rehabilitation services with various cancer related health issues. There were differences between Fern and Willow Therapy Team regarding recruitment numbers, sample size, and participant characteristics. Fern Therapy Team had lower response rate and smaller sample size but had more female interviewees than the Willow Therapy Team. The interviewees recruited from the Fern Therapy Team were also younger, with three participants still actively working. By way of contrast, all participants recruited from the Willow Therapy Team were retired. Moreover, three participants' partners joined the as a companion. Referrals to the cancer rehabilitation services happened through various avenues, including follow-up consultations, education events, and peer support groups. The next section aims to detail the length of the interviews.

### **7.1.3 Length of the interviews**

Interview recordings of people affected by cancer and healthcare professionals ranged from 26 to 96 minutes. Mean interview length was 56 minutes. The shortest interview was conducted with a therapy technician from the Fern Therapy Team, while the longest interview was conducted with a dietitian from the hospital where the Willow Therapy Team is located in. The 35 interviews produced 33 hours and six minutes of audio recordings. Individual timings for each interview can be seen in Appendix 22.

## **7.2 Routinely collected data used for the secondary analysis**

In this section, firstly the overall record numbers available in the routinely collected data database are discussed. The overall record numbers can offer an indication of service uptake and referrals to the exercise classes run by the Willow Therapy Team. Then, the outcome measure data available for statistical analysis is described. In chapter 5 it was mentioned that missing data handling methods were applied, as the database contained a substantial amount of missing outcome measure data. In the following sections based on the guidance of Sterne et al. (2009) a brief summary of missing data is presented, with an exploration of potential patterns of missingness, and possible reasons for absent data. It is

important to discuss the sample size and the amount of missing data, as these can influence the interpretation and generalisability of the findings.

### 7.2.1 Overall record numbers available in the database

The raw database received by the Willow Therapy Team in three Excel files contained 1743 entries: 357 episodes in 2014; 528 in 2015; and 858 in 2016-2017. The 2016-2017 database contained seven records from 2018 and one entry labelled as “unknown” year. These eight records were removed from the analysis. Then, the database was scanned for exact duplicate entries and a further 90 records were removed. In the final analysis 1645 entries were used: 357 from 2014; 524 from 2015; 416 from 2016 and 348 from 2017. The cleaned database was then divided into four years and up to 12 episodes.

Table 17 Number of records in each year and episode derived from the database collected by the Willow Therapy Team

<b>Episode Number</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>	<b>Whole database</b>
<b>0</b>	53	67	5	-	125
<b>1</b>	164	280	292	212	948
<b>2</b>	49	86	58	62	255
<b>3</b>	30	43	22	32	127
<b>4</b>	25	19	13	17	74
<b>5</b>	17	9	7	8	41
<b>6</b>	7	8	6	4	25
<b>7</b>	5	5	4	2	16
<b>8</b>	4	3	4	1	12
<b>9</b>	2	3	2	2	9
<b>10</b>	1	1	-	2	4
<b>11</b>	-	-	-	1	1
<b>12</b>	-	-	-	1	1
<b>Unknown</b>	-	-	3	4	7
<b>Total</b>	357	524	416	348	1645

As previously mentioned earlier in chapter 5, the Willow Therapy Team referred to a 12-week exercise class or individual therapy as an episode. Episodes were numbered from 0 to 12 by the Therapy Team. Episode 0 meant that people were referred to the service, but they did not attend the initial assessment appointment, or attended the initial assessment but subsequently after the initial assessment disengaged from the rehabilitation service. Episode 1 mainly contained participants who attended their initial assessment and/or took part in their first 12-week rehabilitation episode. Episodes 2 to 12 represented participants

who needed further support after their first episode. A few episode numbers were referred to as unknown, as they were missing from the database. Table 17 above shows the number of records available in each year and episode.

The records presented in Table 17 were used to determine referrals and service uptake, as every person referred to the service and attended an initial assessment appointment was documented in the database. Service uptake is discussed further in chapter 8.

### 7.2.2 Outcome measure data available for statistical analysis and missing data

Another main function of the secondary analysis was to investigate how outcome measures changed between a pre and post rehabilitation episode. For these purposes, FACIT-F, TUAG, quality of life, pain and SOB scales were used. These outcome measures were introduced in chapter 5. Tables 18, 19, 20, 21 below show the available sample sizes for statistical analysis from 2014 to 2017. The sample sizes used for comparing pre and post rehabilitation episode data differed from the overall sample size of the database (Table 17). This is due to a large amount of missing outcome measure data. For example, in 2014 compared to the overall number of records (Table 17), the percentage of available outcome measure data varied between 5% (SOB) and 52% (QOL) in episode 1 (Table 18). In the following years, the available sample size increased for SOB, but reduced for the other outcome measures in episode 1. Data available for analysis ranged between 20% (SOB) and 45% (QOL) in 2015, 21% (SOB) and 29% (QOL) in 2016, 16% (SOB) and 29% (QOL) in 2017. These percentages indicate that over the years data was missing between 48% and 95% of the cases in episode 1. In subsequent episodes, the difference between the overall number of records in the database and the outcome measure data reduced slowly. More available and missing data percentages can be found in Appendix 23.

### 7.2.3 Pattern of missingness

Difference in sample sizes was not only noticeable between the overall number of records and the outcome measure data, but between the various outcome measures. This sample size variability was most prominent between SOB and other outcome measures, particularly in 2014. The reason for the variability was that healthcare professionals often did not report measures if participants did not have any issues in the given health domain. Indeed, during the interviews one healthcare professional articulated that the use of outcome measures was based on professional judgement:

*“We tend to do our standard ones [outcome measures] with everybody because it’s recorded on a database, so we use that database then to look at kind of pre- and post-episode, and yeah, so they then tend to be the standard ones, but the range of movement, pain, breathlessness, we only do if it’s an issue for that patient and there are times where you know it’s not appropriate to do some of the outcome measures so I don’t do it, but I just use my judgement I suppose.” (Professional\_15 - physiotherapist)*

Table 18 Sample size available for analysis for each outcome measure and episode in 2014

Episode number	Sample size (n) for each outcome measure in 2014				
	FACIT-F	TUAG	QOL	PAIN	SOB
0	2	2	2	NVC	1
1	55	78	86	32	8
2	26	41	40	13	NVC
3	16	28	28	8	NVC
4	8	22	22	6	1
5	7	14	13	8	NVC
6	4	7	7	5	NVC
7	3	5	5	4	NVC
8	1	4	4	4	NVC
9	1	2	2	2	NVC
10	NVC	1	1	1	NVC
Key: NVC – No valid cases					

Table 19 Sample size available for analysis for each outcome measure and episode in 2015

Episode number	Sample size (n) for each outcome measure in 2015				
	FACIT-F	TUAG	QOL	PAIN	SOB
0	1	NVC	1	NVC	NVC
1	101	112	126	86	57
2	39	46	50	31	15
3	24	29	30	20	6
4	7	6	9	9	1
5	3	4	5	4	1
6	3	3	3	2	NVC
7	1	NVC	1	1	NVC
8	2	2	2	2	NVC
9	3	3	3	3	NVC
10	NVC	NVC	NVC	NVC	NVC
Key: NVC – No valid cases					

Table 20 Sample size available for analysis for each outcome measure and episode in 2016

Episode number	Sample size (n) for each outcome measure in 2016				
	FACIT-F	TUAG	QOL	PAIN	SOB
0	1	NVC	1	NVC	NVC
1	75	74	84	75	61
2	18	15	21	20	15
3	10	8	11	13	13
4	7	6	7	7	7
5	5	4	5	4	2
6	4	4	4	3	1
7	3	2	3	2	2
8	3	1	2	3	1
9	1	NVC	NVC	1	1
Unknown	NVC	NVC	NVC	NVC	NVC
Key: NVC – No valid cases					

Table 21 Sample size available for analysis for each outcome measure and episode in 2017

Episode number	Sample size (n) for each outcome measure in 2017				
	FACIT-F	TUAG	QOL	PAIN	SOB
1	56	40	62	56	33
2	34	25	35	26	16
3	13	14	16	14	8
4	6	4	6	5	5
5	5	3	5	5	4
6	1	2	2	2	1
7	1	NVC	1	1	1
8	1	NVC	1	1	1
9	2	1	2	2	1
10	2	1	2	2	1
11	1	1	1	1	1
12	NVC	NVC	NVC	NVC	NVC
Unknown	NVC	NVC	NVC	NVC	NVC
Key: NVC – No valid cases					

When professional judgement is considered in data collection, it can be presumed that the data is not missing completely at random (MCAR). This is important to establish when dealing with missing data, as the pattern of missingness can influence data handling methods and the generalisability of the findings.

Besides the variability in reporting outcome measures, there were cases where pre rehabilitation episode data was available, but post rehabilitation data was not. Therefore, missingness pattern was further tested with statistical methods described in chapter 5. In this PhD study, to confirm the missingness pattern pre rehabilitation data was compared based on people having post rehabilitation data or not (Dixon 1992). Statistically significant differences between the two group were found in various episodes in 2014, 2015, and 2016. In 2014, statistically significant difference was found in episode 1 for FACIT-F ( $U=521$ ;  $z=-1.964$ ;  $p=0.05$ ;  $r=-0.218$ ) and TUAG ( $U=1924.5$ ;  $z=2.603$ ;  $p=0.009$ ;  $r=0.242$ ). FACIT-F scores were significantly lower pre rehabilitation for people who did not have post rehabilitation data ( $M=20.8\pm19.5$ ;  $Mdn=19.5$ ), than people who had ( $M=25.6\pm10.8$ ;  $Mdn=24$ ). TUAG times were higher in people with missing post rehabilitation data ( $M=11.4\pm5.4$ ;  $Mdn=9.5$ ), than people who had available post rehabilitation TUAG ( $M=9.1\pm4.3$ ;  $Mdn=7.6$ ). This supports that outcome measure data was not MCAR.

In 2015, statistically significant difference was found in episode 2 for FACIT-F ( $t(64)=2.377$ ;  $p=0.02$ ;  $r=0.285$ ). FACIT-F scores were significantly lower pre rehabilitation for people who did not have post rehabilitation data ( $M=26.296\pm10.325$ ;  $Mdn=27$ ), than people who had ( $M=32.590\pm10.745$ ;  $Mdn=35$ ). In 2016, there was a statistically significant difference in pre rehabilitation QOL ( $U=3.744.5$ ;  $z=-2.457$ ;  $p=0.014$ ;  $r=-0.176$ ) and pain ( $t(43)=2.042$ ;  $p=0.047$ ;  $r=0.297$ ) scores in episodes 1 and 2, respectively. People whose QOL data was missing post rehabilitation ( $M=54.866\pm22.371$ ;  $Mdn=50$ ) had a significantly lower QOL pre rehabilitation, than people who had available follow-up data ( $M=61.619\pm18.852$ ;  $Mdn=65$ ). People who had missing post rehabilitation pain data had a significantly lower pain level pre rehabilitation ( $M=3.514\pm1.993$ ;  $Mdn=3.6$ ), than people who had available post rehabilitation data ( $M=4.825\pm2.313$ ;  $Mdn=4.5$ ). These findings further indicate that the missing data pattern was not MCAR. This means that data missing post rehabilitation was not by chance, and certain factors might have influenced why some people did not have post rehabilitation data. One of the reasons could be the variability in reporting by professionals based on their judgement. However, based on Professional\_15's interview extract that mainly affected pain and SOB. Therefore, the reason for the pre rehabilitation data difference in QOL and TUAG needed further investigation.

Chi square test was performed in the episodes where significant difference was found in pre rehabilitation data to determine what possible factors had some association with missing data post rehabilitation. Data was coded based on availability and missingness of

post rehabilitation outcome measures, and coded variables were cross tabulated with discharge codes. In 2014, for FACIT-F in episode 1, data missingness had a statistically significant association with three discharge codes: “assessment only” ( $\chi^2(1)=7.173$ ;  $p=0.009$ ); “did not attend” (DNA) (Fisher's Exact (25%);  $p=0.015$ ); and “refused scheme” ( $\chi^2(1)=15.383$ ;  $p=0.000$ ). Association with “assessment only” meant that some people who did not have post rehabilitation FACIT-F data attended the initial assessment but did not engage with the service in the longer term. DNA referred to people not attending the initial assessment, and “refused scheme” meant that people did not want to attend the exercise classes after initial assessment. For TUAG in episode 1, 2014 “assessment only” ( $\chi^2(1)=15.693$ ;  $p=0.000$ ), “disengaged” (Fisher's Exact (50%);  $p=0.013$ ), DNA (Fisher's Exact (25%);  $p=0.001$ ), and “refused scheme” ( $\chi^2(1)=28.808$ ;  $p=0.000$ ) discharge codes had associations with missing post rehabilitation data. These were similar to the associations between FACIT-F and discharge codes, although TUAG also correlated with the code “disengaged”, meaning that people who disengaged from the service had more missing data than people who stayed for post rehabilitation assessment. Therefore, disengagement could be behind some of the missing data.

In 2015, for FACIT-F in episode 2, there was a statistically significant association between missing data and the discharge code “disengaged” ( $\chi^2(1)=17.987$ ;  $p=0.000$ ), indicating that data was missing post rehabilitation because people affected by cancer disengaged from the exercise classes. In 2016, for QOL in episode 1 missing post rehabilitation data had a statistically significant association with the following discharge codes: “assessment only” ( $\chi^2(1)=9.310$ ;  $p=0.001$ ), “disengaged” ( $\chi^2(1)=18.059$ ;  $p=0.000$ ), DNA (Fisher's Exact (25%);  $p=0.004$ ), and “refused scheme” ( $\chi^2(1)=27.922$ ;  $p=0.000$ ). In addition, there was a statistically significant relationship between missing post rehabilitation QOL, “health deterioration” ( $\chi^2(1)=13.600$ ;  $p=0.000$ ), “inappropriate referral” (Fisher's Exact (25%);  $p=0.021$ ) and people who died (RIP discharge code) (Fisher's Exact (25%);  $p=0.035$ ). These associations between QOL data and discharge codes could indicate that besides disengagement, health deterioration and people dying might have influenced the amount of missing data. For pain in episode 2 in 2016 association was found between missing post rehabilitation data and “health deterioration” discharge code (Fisher's Exact (50%);  $p=0.037$ ). This indicates that participants whose health deteriorated over the course of the 12-week exercise class might have stopped attending the services early, leading to missing post rehabilitation data.

#### 7.2.4 Summary of routine data used for secondary analysis

This section introduced the routine outcome measure data collected by the Willow Therapy Team. Overall record numbers available in the database were presented that could be used to estimate service referrals and uptake. Outcome measure data was explored as sample sizes differed from the overall record numbers, highlighting a substantial amount of missing data in the database. Data was missing due to variability in reporting based on professionals' judgement on the appropriateness of the outcome measures, and potentially because some people affected by cancer experienced health deterioration and/or disengaged from the exercise classes run by the Willow Therapy Team. Exploring the routine data before discussing the findings is important as the attributes of the data could influence interpretation and generalisability of the findings. These exploratory investigations into the database also highlighted issues with disengagement from the service. This could indicate that cancer rehabilitation in the form of exercise classes does not necessarily work for everyone.

### 7.3 Conclusion

This chapter introduced the data used for the realist evaluation of cancer rehabilitation services in South Wales. Thirty-five qualitative interviews were conducted with people affected by cancer and healthcare professionals to investigate the mechanism and context that make cancer rehabilitation work. A wide range of AHPs and people with different cancer sites and backgrounds participated in this PhD study for a comprehensive investigation of the two services. In addition, the routine data collected by the Willow Therapy Team was explored, showing available and missing data. Introducing the data can ensure transferability and validity of the findings. The next chapter presents the findings based on the data presented here.



## Chapter 8: Information on and awareness of cancer rehabilitation services

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In this chapter, the findings of the data analysis regarding IPT\_1, first presented in chapter 4, focusing on information and awareness of cancer rehabilitation services. For ease, IPT\_1 is revisited below:

**IPT\_1:** Raising awareness on available cancer rehabilitation services, and appropriate information on their purpose (**mechanism**) can increase the uptake of rehabilitation and scheme attendance (**outcome**) if people's perception and attitudes are supportive of cancer rehabilitation (**context**).

Data collected throughout this study was compared to IPT\_1 to see if information provision on cancer rehabilitation services and raising awareness works in the real world as expected. Firstly, the outcomes will be explored, as if the outcomes differed from the IPT, it indicated that new CMOs needed to be developed to explain how cancer rehabilitation services worked.

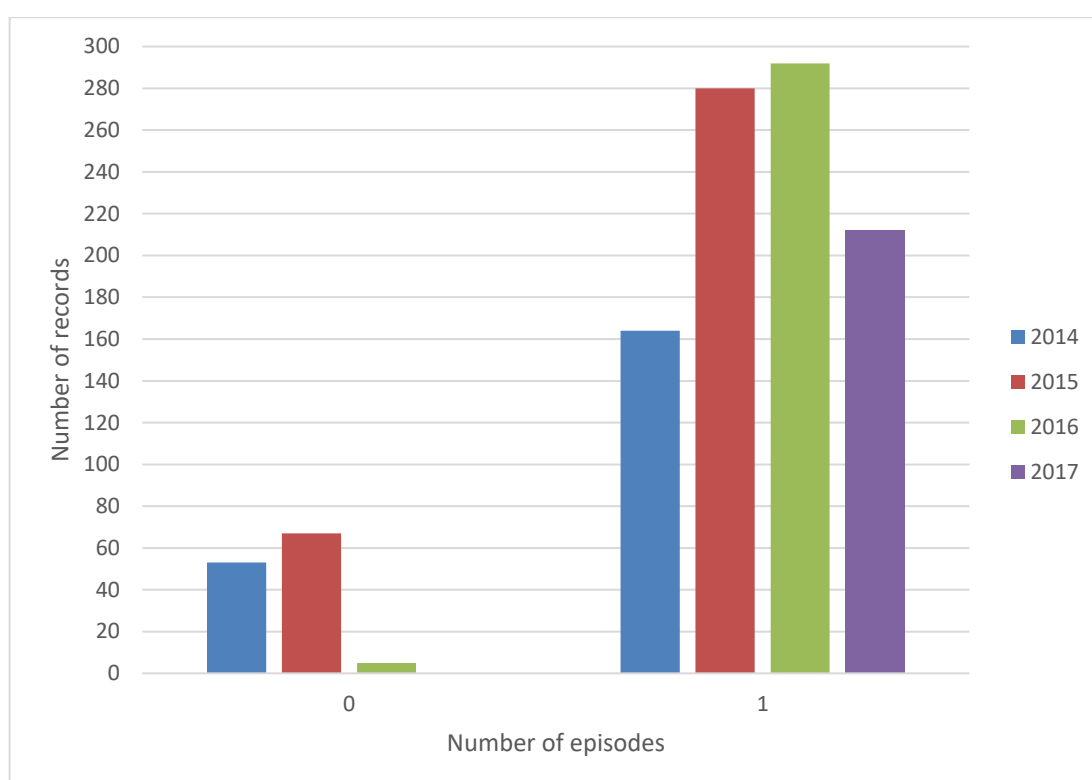
### 8.1 Outcome – Uptake and scheme attendance

#### 8.1.1 Service uptake of the Willow Therapy Team

To determine service uptake and referrals to the Willow Therapy Team exercise classes, the overall record numbers from the database were used. Episodes 0 and 1 were introduced in chapter 7. These two episodes reflect referrals, booked initial assessment appointments, and the first 12-week rehabilitation episode. However, the difference between episodes 0 and 1 is, that people who had an episode 0 booked in for an appointment with the Willow Therapy Team, but they did not attend (DNA), or disengaged from the Willow Therapy Team following the first appointment. People who had episode 1 usually attended their first appointment and engaged in the exercise classes. Therefore, these two episodes could give an indication on service uptake. Figure 10 below graphically presents the number of participant records over the years and episodes at the Willow exercise classes. The number of records observed in episode 0 increased in 2015 (n=67) compared to 2014 (n=53). This could indicate that the number of people who did not attend their initial assessments increased. However, the number of records for episode 1 almost doubled in 2015 (n=280) compared to 2014 (n=164), indicating that overall, more people had appointments booked

and started rehabilitation in 2015 than in 2014. Adding episode 0 and episode 1 together, it may be read that in 2014, 217 referrals were made to the Willow Therapy Team, while in 2015 347 people had initial assessment appointments booked or started the 12-week cancer rehabilitation.

Figure 10 Number of participant records identified for each episode per year as part of the secondary analysis of routinely collected data by the Willow Therapy Team

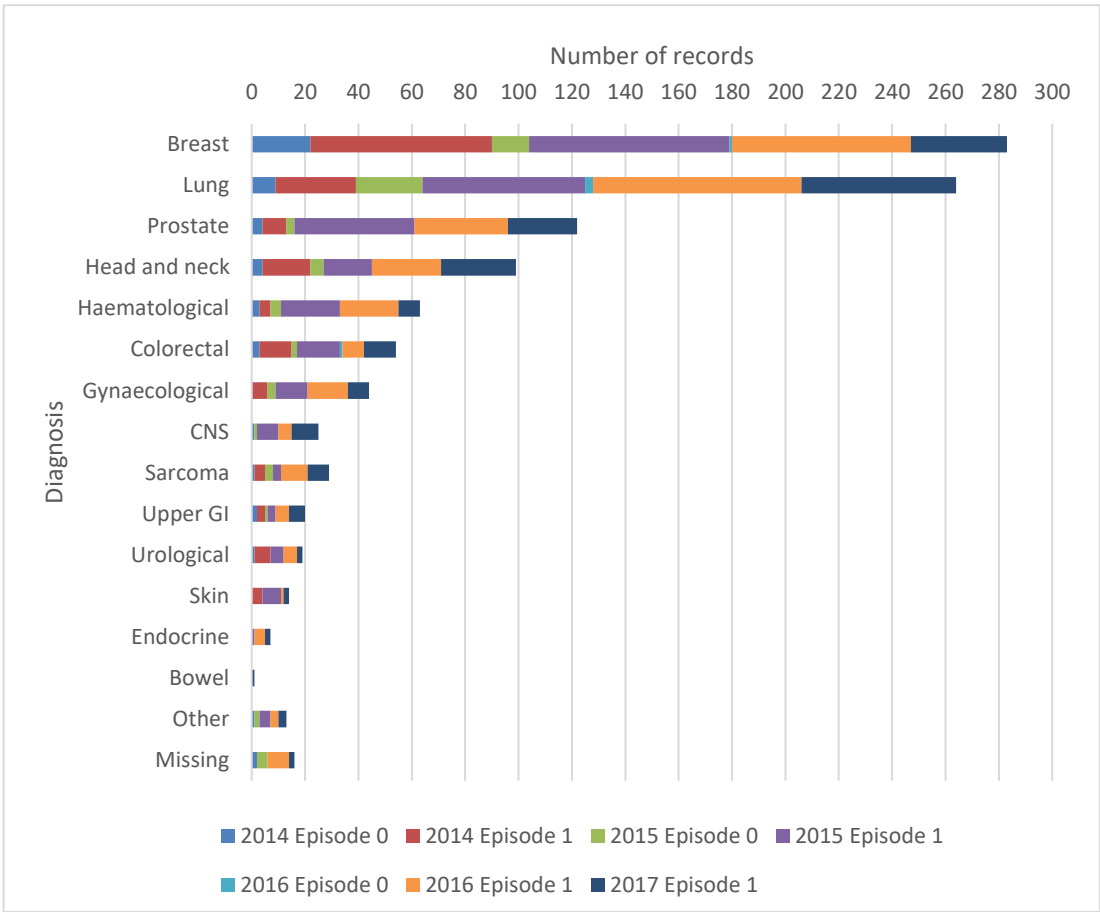


In 2016, episode 0 numbers drastically reduced ( $n=5$ ), although episode 1 increased ( $n=292$ ) compared to episode 1 in 2015. However, when adding episode 0 and episode 1 together, it can be observed that the overall number of referrals in 2016 ( $n=297$ ) was below the 2015 rate ( $n=347$ ). In 2017, no episode 0 was reported, and episode 1 showed a further decline in new cases ( $n=212$ ) compared to 2015 and 2016. This fluctuation in uptake over the years could indicate two things: either that service uptake and referrals changed, or that the rehabilitation needs of people affected by cancer fluctuated. To further investigate service uptake, the referrals for different diagnoses and gender were explored.

Figure 11 below shows the different cancer diagnoses in episodes 0 and 1 over the years. Breast ( $n=283$ ) and lung cancer ( $n=264$ ) were the two most dominant diagnoses among cancer rehabilitation attendees. This reflects the rate of new local cancer cases, as breast ( $n=1391$ ) and lung cancer ( $n=1302$ ) were the two most prevalent diagnoses from 2014 to

2017 (Welsh Cancer Intelligence and Surveillance Unit 2019). Colorectal cancer ( $n=1137$ ) had the third highest number of new cases between 2014 and 2017 in the local area (Welsh Cancer Intelligence and Surveillance Unit 2019), although this did not reflect in uptake numbers to the Willow Therapy Team ( $n=54$  between 2014 and 2017). Even though, there is emerging evidence that a high proportion of colorectal cancer patients have physical and psychological rehabilitation needs (Wiedenbein et al. 2016). Prostate cancer ( $n=1086$ ) had the fourth highest number of new cancer diagnoses within the local University Health Board between 2014 and 2017. However, although men can face severe long-term and late effects (Hyde et al. 2017), between 2014 and 2017 only 122 people affected by prostate cancer were referred to rehabilitation. Moreover, the Willow Therapy Team did not collect data on their inpatient ward activity, so it is possible that they saw more people affected by cancer than what was reported in the database.

Figure 11 Diagnosis distribution differences in case records in episodes 0 and 1 over the years

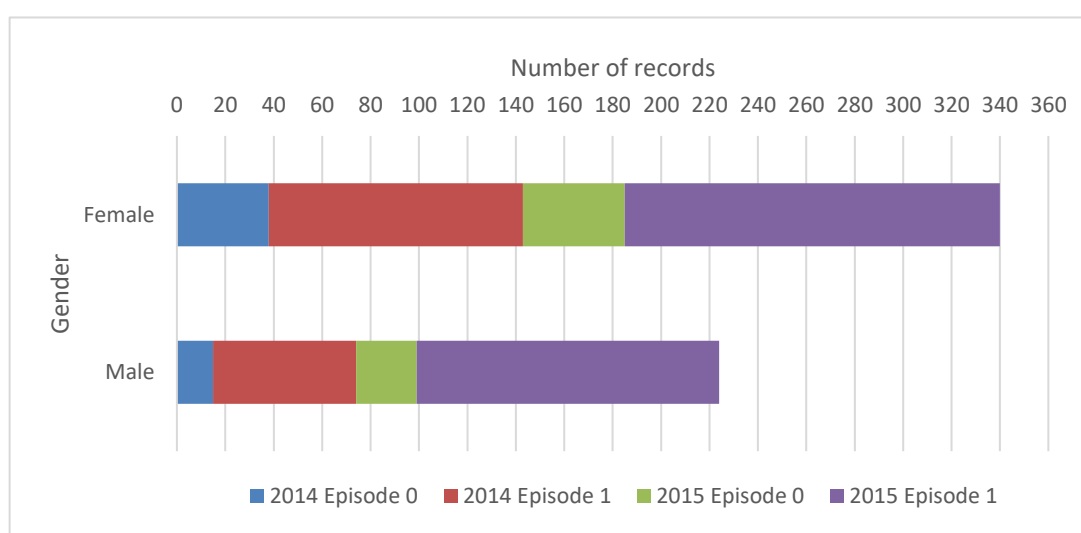


Variations in service uptake among different cancer sites were observed over time. Referrals of people with breast cancer reached a peak in 2015 ( $n=22$  in episode 0 and  $n=75$

in episode 1) and dropped in 2017 ( $n=36$ ), halving the previous years' uptake. Lung cancer cases peaked in 2016 ( $n=3$  in episode 0 and  $n=78$  in episode 1) and dropped in 2017 ( $n=58$ ). In addition, the decrease in the number of people in 2017 was noticeable in other cancer sites, such as prostate, gynaecological and haematological cancers. However, uptake amongst people with central nervous system (CNS), head and neck and upper gastrointestinal cancers increased in 2017 as did the uptake of those with colorectal cancer ( $n=12$ ) compared to 2016 ( $n=1$  in episode 0 and  $n=8$  in episode 1).

When investigating gender, a major difference can be noticed between the uptake of male and female exercise class participants. Figure 12 shows that in 2014 and 2015 more female ( $n=340$ ) participants were referred to the Willow Therapy Team than male ( $n=224$ ). Gender data was only available for 2014 and 2015 due to changes in how the Willow Therapy Team collected data. In 2014 almost twice as many women ( $n=38$  in episode 0 and  $n=105$  in episode 1) were referred to the rehabilitation services than men ( $n=15$  in episode 0 and  $n=59$  in episode 1). However, in 2015 the number of men contacting the Willow Therapy Team doubled ( $n=25$  in episode 0 and  $n=125$  in episode 1). The increased uptake by men could be attributed to the uptake increase of men with prostate cancer.

Figure 12 Gender differences in case records in episodes 0 and 1 over 2014 and 2015



The number of men with prostate cancer referred to the service almost quadrupled from 2014 ( $n=4$  in episode 0 and  $n=9$  in episode 1) to 2015 ( $n=3$  in episode 0 and  $n=45$  in episode 1). These changes were not in line with the annual new diagnosis rate in the local health board. In 2014 and 2015, 228 men were diagnosed with prostate cancer each year. Therefore, the sudden increase in prostate cancer uptake of the Willow Therapy Team

cannot be explained with a raise in new prostate cancer diagnoses. Exploring the mechanisms and context that influence referral numbers can help understand the causes of annual fluctuations in service uptake and variations in diagnoses and gender distribution.

#### 8.1.2 Service uptake of Fern Therapy Team

Based on the interviews, referrals to the Fern Therapy Team were mainly from nurses or MDT members. Professionals articulated that the number of people they were seeing for therapies varied, depending on people's needs.

*"It [number of people affected by cancer seen] really does depend. We could have a day where sort of maybe, might be three patients seen. Where it could be another day, where we're all seeing patients back to back. There's no, that's the one thing you're finding in working in this setting is there's no consistency, so, you know it could be really quiet, and then the next day, there could be three fast track patients on the ward, there could be urgent cushion referrals come in. It's quite hard to plan that sense." (Professional\_12 – OT)*

*"It [number of people affected by cancer seen] really varies so, because we cover the wards. So, all of the wards here will, will be... will see patients, so that can vary depending on how busy the wards are, but generally Monday, Wednesday, Friday we cover wards, so we could see up to five to ten patients on the wards between us, and then head and neck clinics are designed, so we sit in and see every single patient, [...]" (Professional\_07 – dietitian)*

*"Yeah. Can be... can be really really busy. It's peaks and troughs, I don't know why they can't seem to come through together. Hahaha [laughing] But yeah, no, on the whole it's probably a good ten patients in a session." (Professional\_09 – SLT)*

These accounts indicate that uptake for an intervention or an input from a cancer specialist AHP was mainly dependent on the hospital population's needs. The data extracts suggest that healthcare professionals were trying to see as many people as their staff capacity allowed.

Most interventions were one-to-one, although the OT team offered fatigue management groups. Regarding attendance of the fatigue management group, professionals' responses were conflicting. While Professional\_03 mentioned that attendance at fatigue management groups were good, Professional\_04 claimed the opposite, saying that attendance could have been anything between two to five people:

*"We normally find that attendance is pretty good. And obviously week one we do always say 'If you can't attend, please let us know by a phone call just we don't worry about you really.' So no, attendance is pretty good." (Professional\_03 – Technician)*

*“[...] so we do like a... fatigue management course. And again, I wouldn’t say they are very well attended. You can get anywhere between kinda two and five patients at a time. But you know thousands of patients come through, outpatients that you know would be suffering with fatigue, so why they’re not accessing that [...] yeah it’s quite... you know the turnout it’s quite poor from... from that.”* **(Professional\_04 – Dietitian)**

Possible explanation for the difference between the two professionals’ accounts could be that Professional\_03 was quite new to her role as an OT technician. She had worked for the Fern Therapy Team for over a year, although she worked with the physiotherapists previously. Nevertheless, Participant\_37 seems to confirm that fatigue management group uptake and attendance might be low:

*“So, there were only four or five of us I think [...] I think probably it could have bigger groups with more people. I don’t know what the demand’s like, but I think it would have been nicer for me, if there had been more people I could identify with on that course [...]”* **(Participant\_37 – person affected by breast cancer)**

While the one-to-one services provided by the professionals were more formal appointments closely tied in with inpatient stay or MDT consultations, attending a four-week long fatigue management group was a more voluntary activity for people affected by cancer, similar to the exercise groups by the Willow Therapy Team. Therefore, these qualitative findings could indicate that issues exist with the uptake of voluntary group rehabilitation classes. The next section introduces the findings related to the mechanism, which provides some answers regarding potential issues with uptake.

## **8.2 Mechanism – information provision on and raising awareness of cancer rehabilitation services and treatment related side effects**

Initially, it was theorised that providing information on and raising awareness of available service was the mechanism leading to increased uptake. However, issues were identified with the mode information provision as people learnt about the cancer rehabilitation services in various ways. The lack of consistency in how information was provided led to late referrals and reduced rehabilitation service uptake. Moreover, based on the interviews another function of information provision was explored namely, to increase people’s knowledge on their cancer related side effects.

### 8.2.1 Mode of information provision

Issues with the mode of information provision refer to the ways in which people affected by cancer learnt about cancer rehabilitation services. This included being provided with information on cancer rehabilitation services or referred by the wider MDT, information from a local support centre, education courses and information leaflets.

#### 8.2.1.1 Information about and referral to cancer rehabilitation through the wider MDT

Seven participants recruited from the Willow and Fern Therapy Teams learnt about rehabilitation services from oncology nurses, their oncologist or even from AHPs working in other settings. Two out of seven participant were unsure of the correct professional title of the person who assisted with their rehabilitation needs, but from their description it could be assumed it was an oncology nurse. Some of the participants mentioned that they only received information on cancer rehabilitation services when they explicitly raised concerns about their cancer treatment related side effects. These issues were identified for both Willow and Fern.

*“I only found out about those [acupuncture, counselling] services, cos I talked about my symptoms. Some people might not mention those symptoms in a meeting for whatever reason. I think it would be helpful maybe if you... they could delve in a bit more to what was going on with you.” (Participant\_21 – person affected by breast cancer)*

*“[Willow exercise classes] It was offered to me when I went for one of my bi-monthly checks with the oncologist. I don’t know who, the oncologist or one of the pharmacist, but I went in and I said ‘You know, I’m very very concerned at the amount of weight I’ve put on. All around my middle and...’ I said ‘Nothing I seem to do... works, and you know, works... I’ve tried dieting but that doesn’t really work at my age. So they said ‘Would you like to... do a course of exercises?’[...]” (Participant\_30 – person affected by cancer)*

The issue with raising concerns often stemmed from that people did not want to be a burden for healthcare professionals, or they were unaware who they could discuss their health concerns with. Indeed in the following data extract Participant\_10 and his partner expressed frustration that they could not recall receiving any information from their local hospital regarding his referral to the Cancer Centre for treatments. They felt getting help for him happened by chance and while he was referred to the Willow Therapy Team, they said earlier rehabilitation input would have been better.

*“Companion\_10: We didn’t know... anything. All we were told was... you go to [cancer centre], you are... present yourself to the oncology clinic, you have your treatment. There was one other girl we spoke to in there, we had a... an interview with her halfway through?”*

**Participant\_10:** *Yes, that's right. I can't recall what her name was...*

**Companion\_10:** *I can't think of her name now, but hm... she was very good, she referred you to the dietitian.*

**Participant\_10:** *That's right.*

**Companion\_10:** *And I believe it's through her that we... was it through her we ended up seeing Therapist\_03?*

**Participant\_10:** *I'm not sure, I'm not sure, but I think it may well have been.*

**Companion\_10:** *But after the last session of... hm... radiotherapy hm... we were then given an appointment to see Therapist\_03 and... I agree that if you'd seen Therapist\_03 before...*

**Participant\_10:** *It would have been a big help."*

Participant\_29 said he was informed about and referred to fatigue management by his oncology nurse specialist. However, he had previously mentioned his fatigue to his doctors. From his description, both doctors seemed dismissive of his problem, resulting in late referral to the fatigue management group.

*"[...] One of the nurse specialists in urology in the [hospital name]. I mentioned fatigue there. A couple of times I... when I mentioned fatigue, when I was seeing, seeing the urologist they kind of said 'Fatigue? That's your age.' And they didn't kind of... connect with that at all. Or they would say or... a different consultant would say 'Oh, that's unusual' as the fatigue progressed, I spoke to one of the nurse specialists and she suggested Fern."*  
**(Participant\_29 – person affected by prostate cancer)**

Participant\_02 got in touch with the Willow Therapy Team through attending the physiotherapy department of her local hospital. Participant\_02 experienced deconditioning as treatment related side effect and would have liked to receive some light exercises. However, the physiotherapist who saw her in her local hospital could not help her, so she referred her to the Willow Therapy Team. Although, she received treatments at the hospital where the Willow Therapy Team operated, she only learnt about the Tai Chi classes after a physiotherapist in her local hospital phoned around the University Health Board.

*"They referred me then to the Willow nurses. I had no idea that the Willow nurses did anything like that, nobody'd given me that information. So, I... it was self-help really that got me there and hm... when I had my first appointment with them, they suggested some... hm... Tai Chi or sim... other thing and I choose Tai Chi [...]"* **(Participant\_02 – person affected by colorectal cancer)**

Participant\_09 and Participant\_37 had fairly straightforward access to rehabilitation, with their oncology nurses or oncologists referring them to the Willow and Fern Therapy Teams when they articulated their health concerns.

*"The nurse who's managing my Zometa, she was just... with... they tend to telephone consultations before each treatment, and the last one in January, she was just chatting to me about how I was coping with everything? And I just said 'Oh, I'm struggling, I'm getting*



*really tired' And that's when she referred me [to the fatigue management group]."*  
**(Participant\_37 – person affected by breast cancer)**

#### *8.2.1.2 Information from a local support centre*

Three participants learnt about the Willow Therapy Team through accessing a local third sector organisation support centre (Pine Centre). Participant\_01 attended a prostate cancer education course, which included a physical exercise session. During this physical exercise session Participant\_01 realised he needed physical activity and asked the organiser where he could attend exercise classes for people affected by cancer. This could indicate that raising awareness could help people realise their rehabilitation needs and highlight services that could assist them with improving their quality of life. However, Participant\_01 acknowledged that he might not have learnt about the existence of the Willow Therapy Team if it was not for Pine Centre.

*"And I happened to say to Pine professional 'I really need to do something more. Where can I go?' She said 'I put you in touch with the Willow people.' And that's how I knew. [...] I may not have known about it, had I not come that way. You know, because, when you are confronted with something and you're having to learn a new career... much like getting over life... when you are in the middle... you know... of all that... you don't, where you get your information it may depend on a member of your family."* **(Participant\_01 – person affected by prostate cancer)**

The other two participants learnt about the Willow Therapy Team through Pine Centre's peer support groups. However, Participant\_12, Participant\_16, and Companion\_16 expressed their frustration for without the peer support group, they would not have learnt about the Willow Therapy Team.

*"[...] It was the rumour you see. Pine Centre, cos they can... they're well connected from here to the same hospital. Pine Centre. Pine Centre told me and I did, I made contact here, huuuu must be... well over a year ago. And I didn't know that the pool existed. I didn't know it [hydrotherapy] would help me. I didn't know there was a pool in Yew Hospital, you see, that's another thing."* **(Participant\_12 – person affected by prostate cancer)**

*"If we didn't go to Pine Centre, we wouldn't have learnt about the Willow nurses, and the only... myself I only know about Willow nurses when it's the end. When they have comfort palliative care. I didn't know that they did things all the way through, and that would be a very good things to have it... more advertised."* **(Companion\_16 – Participants\_16's wife)**

Neither participant could recall if any oncology professionals during had mentioned that the Willow Therapy Team was located in the hospital where they received their treatments. In addition, Participant\_37 mentioned that finding out what services were available was

through word of mouth, thereby indicating that there was a lack of information provided by healthcare professionals at hospitals:

*“I would say that support seems a bit disjointed in terms of getting the information and most of the things that I found out about it’s through the support group, the [...] group, that there are... I’ve met up with them quite a lot, and you... if you speak to people they’ll say ‘Oh, well, I’ve just had aromatherapy or acupuncture or something...’ And you’re like ‘Oh, well, I didn’t know that you can get that.’ ‘Oh, if you need to speak to this person and this...’ You know, so it’s seems to be more word of mouth, there doesn’t seem to be a formal kind of way of finding things out.”* **(Participant\_37 – person affected by cancer)**

#### **8.2.1.3 Education course**

Participant\_03 learnt about the exercise classes through an education course organised for people affected by breast cancer. However, Participant\_03 mentioned that she knew before the course that the Willow Therapy Team existed, she just did not know how to access it.

*“Well, I mean I knew Willow was there, but I wasn’t... I didn’t know how to access them. But then I found out that they were one of the presenters at the course, so after they’d sort of hm... I think it was Therapist\_01 and another woman came in, and said about all the things they did and I thought ‘Ah, that’s what I want, that’s where I need to go’ you know so it was a question of being guided into the Willow services, you know what they do.”* **(Participant\_03 – person affected by breast cancer)**

#### **8.2.1.4 Information leaflets**

Participant\_18 mentioned that she learnt about acupuncture by receiving a leaflet, she received at a radiotherapy clinic, although she could not recall exactly who gave the leaflet to her. This indicates that written information to raise awareness of existing cancer rehabilitation services could be helpful to increase knowledge and, could lead to increased uptake.

*“Well, cos it on the form... one of the forms it says about me approaching Fern to ask for therapies. Well, I didn’t even know there were therapies, so that... it came to me, rather than me going to them. And they just said would you be interested in acupuncture for your hot flushes and reflexology and pilates, so it was just those three things.”* **(Participant\_18 – person affected by cancer)**

Moreover, while Participant\_16 was referred to the Willow Therapy Team through a peer support group at Pine Centre, he received a leaflet from his general practitioner (GP) advertising Pine Centre, facilitating his access to support services. Participant\_16 said that the Pine centre leaflet should be given out to everyone.

*“But then I went back to my GP and doctor said ‘Right’ went in the drawer and gave me this little booklet.*

*‘Participant\_16’ no messing about’ she said ‘The lady said you need to go there’ And the pamphlet was Pine Centre. And I never looked back Judit, what I learned there.”*  
**(Participant\_16 – person affected by prostate cancer)**

However, some information leaflets contained minimal information on support services. Indeed, participant\_12 highlighted that while he received a bulky prostate cancer booklet, it contained just a page on support services, highlighting two or three support services and their contact details. Barely a sentence provided on what the support services were, but no detailed explanation.

*“[...] right at the back. There’s a little thing here. And it’s under the how can I help myself? Get more it is on the how to help yourself from [Charity Cancer Support], [Pine Centre], and [Cancer Charity] thing. That’s it. That’s all there is. And you don’t... what any of those are. That is just not enough.”* **(Participant\_12 – person affected by prostate cancer)**

Moreover, the contact details of one support centre was for London, rather than local services. Participant\_12 felt that written information should contain reference to local services which are accessible to people affected by cancer.

*“Pages of image, just that, and it’s a London number. So that doesn’t help.”* **(Participant\_12 – person affected by prostate cancer)**

#### **8.2.1.5 Summarising the mode of information provision**

Based on interview participants’ experiences, there was no one way people learnt about the cancer rehabilitation services. This was noticeable regarding both the Willow and Fern Therapy Teams. Information provision seemed to work to help people gain knowledge about rehabilitation, although information came mainly from third sector providers or through individuals’ own information seeking behaviours. Arguable, if people lack confidence to raise concerns at consultations or do not want to take part in peer support groups or education courses, they might not learn about other cancer rehabilitation services which could potentially help them. This is a possible context that could influence information provision and service uptake. Written leaflets promoting cancer rehabilitation services can be useful, although only if they contain sufficient information and direct contact details to local rehabilitation and support services. Moreover, self-seeking information or waiting for education courses, often led to late referrals to cancer rehabilitation and issues with timely care.

## 8.2.2 Information provision to increase people's knowledge about cancer treatment related side effects

Some of the interviews indicated that insufficient information was not only an issue with finding appropriate cancer rehabilitation and support services, but with learning about cancer treatment related side effects. This manifested in different ways, from insufficient written information to receiving information late, which could lead to emotional issues and late referrals to rehabilitation services.

### 8.2.2.1 Insufficient written information

As mentioned above, Participant\_18 praised that an information leaflet helped her receive acupuncture for her hot flushes, although she admitted that not all written information she received was sufficient. This highlights a mechanism regarding information provision that could have serious consequences. The role of written information is to offer knowledge on people's diagnosis, treatments, possible side effects, support services and self-management. However, these information leaflets often caused more issues than they solved. Participant\_18 mentioned that although she understood information leaflets needed to cover the different types of breast cancers and treatment options, some may induce stress in a more anxious person:

*"The booklets if you were of that sort of mind [anxious personality], you could... you could worry more reading the booklets. And I know that they've gotta tell you all the scenarios, the booklets didn't bother me, I just thought well, if that's what's to be expected 'Oh, well' or could happen or what it didn't worry me, but I thought if somebody else who was an anxious, worrying type of person who was... cos cancer, the word cancer usually throws ev... most people into panic station [inaudible], doesn't it? That they could be... they could be quite shocked as to what could happen then."* (Participant\_18 – person affected by breast cancer).

In contrast, Participant\_21 mentioned that while there was abundant information in the leaflets about immediate physical side effects, long-term and emotional side effects were not mentioned. This increased her uncertainty about the symptoms and side effects she was experiencing:

*"It was more to do with the sort of physical side effects. It didn't really talk about the emotional side of it much at all. And it didn't... I think it was more like the immediate side effects rather than this is what you might experience more in the longer term, if that makes sense. Like the longer term wasn't really explained, so now you're left thinking 'Oh, it's...' You know, I mean I sort of got on with it, but then I do think 'Oh, is... is this still normal at*

*this stage? Or should I be telling somebody about it?’ And you just don’t know really.”*  
**(Participant\_21 – person affected by breast cancer)**

On a positive side, Participant\_21 praised the written information she found on the webpage of a UK third sector organisation. She felt their documents and leaflets were easy to read and understand, thereby suggesting written information can be helpful if it contains the right information:

*“[...] I find the [Third sector] ones [leaflets] are easier to read, and I don’t know, it’s just the wording of them is better and they go into a bit more detail as well. So, cos I know I find the Herceptin ones we... was really useful for I had the Herceptin and the chemotherapy ones were useful as well. So yeah. And it’s just got loads of information like when I got my diagnosis I could read up about the type of cancer I had on their, and it was really clear.”*  
**(Participant\_21 – person affected by breast cancer)**

Some information leaflets were perceived as being too technical, containing medical language. Participant\_02 explained that reading them often caused her difficulty. She also highlighted that people with special needs may not be able to read what is written in the information leaflets, as she had experience in working with people who have special needs.

*“It’s... the other thing is if they’ve given you all this written information and what about people who can’t read them? I mean having taught for many years in special needs and there were people there that would leave school that still couldn’t read. Not necessarily because they weren’t trying, obviously because they didn’t have the intelligence, but... but severe dyslexia and whatever. Would they bother, because you’ve got an aversion then to reading, so therefore you wouldn’t even necessarily ask anyone else to read it for you, do you know what I mean? You wouldn’t... so you’re gonna miss out on all that information.”*  
**(Participant\_02 – person affected by colorectal cancer)**

Similarly Participant\_12 considered that not being able to read information can lead to people having insufficient information. Participant\_12 suggested that attending peer support groups to learn about cancer and support services is more valuable than another leaflet.

*“I’m not here to do... to just push [Pine Centre], but it was far better for me and the others the information we got right at the beginning of our problem, far better than all these booklets handing out, cos you... you’ve gotta read it for a start, and if you don’t understand reading, pull down on you.”* **(Participant\_12 – person affected by prostate cancer)**

In addition, Participant\_12 mentioned that the prostate cancer leaflets were too technical.

*“And you try and read that and you... you don’t know what you’re reading, you don’t know anything about it. It’s massive.”* **(Participant\_12 – person affected by prostate cancer)**

This could have led to lack of knowledge on possible side effects and support that could be accessed.

#### **8.2.2.2 Lack of early information input and support**

Some participants mentioned that they often did not receive timely information regarding side effects and this often led to anxiety and stress as the following data extract reveals:

*“No one really explained the biggest problem that I had personally in that was the tiredness. And no one really explained to me that... that would be a... an issue. [...] I was... at that time I was... so tired, it was crazy and so low and depressed...”* **(Participant\_10 – person affected by prostate cancer)**

*“Maybe some of that [depression] could have been alleviated if I’d had some knowledge before I started radiotherapy.”* **(Participant\_10 – person affected by prostate cancer)**

*“I think there’s just been so much more now, but as we said before, if we could have had more information and more help beforehand, we would have been better prepared for going through this [cancer] again.”* **(Companion\_10 – person affected by prostate cancer)**

Participant\_10 and Companion\_10 mentioned that while they received an information booklet on Prostate-Specific Antigen (PSA) results, only Companion\_10 read it and she did not find it useful. Healthcare professionals might need to consider people’s information provision preferences when trying to increase knowledge on cancer related symptoms and side effects. Moreover, Participant\_10 mentioned that accessing the Willow Therapy Team earlier, would have been helpful for him. This was supported by Participant\_12’s account who asked others from his peer support group on how they found information, support, and rehabilitation throughout the cancer pathway. Participant\_12 and his friends from the prostate cancer peer support groups highlighted that the worst part of their pathway was the first couple of months post diagnosis, due to insufficient information and support.

*“My research says the first 3 months [post diagnosis] were the worst, or the first week [post diagnosis] was by far the worst and the general feeling at Pine Centre, which is 18 people plus myself, and plus a couple of people in the pool that I know. The first week is terrible. They come out confused [post diagnosis], completely confused, extremely depressed and the information that’s given to them is not delivered very well. And it’s not got enough information in it.”* **(Participant\_12 – person affected by prostate cancer)**

This data extract highlights that people affected by cancer might need more emotional, psychological, and informational support right from the diagnosis, to help cope with cancer, the treatments and side effects. However, information provision and emotional support

must be based on people's needs and as Professional\_03 highlighted, there are people who do not want to know about their cancer.

*"They [patients] don't want to know about their disease, the family know about it, and they know what's gonna happen, but the actual patient, they don't want to know about the disease, they don't want to know if it's spread somewhere else, they don't want to know how long they've got left. And that is sometimes quite tricky, hm when we trynna sort out discharge plan remembering, that who knows what and who doesn't."* **(Professional\_03 – Technician)**

None of the participants affected by cancer interviewed in this study indicated that they did not want to know about their disease. All were keen to know more and have sufficient information. In addition, Companion\_16, Participant\_16's wife highlighted, that not knowing the side effects of the hormone therapy her husband received endangered their marriage. Participant\_16 had mood swings which strained their marriage. However, attending the peer support group helped Companion\_16 understand what Participant\_16 was experiencing, and participating in the Willow Therapy Team exercise classes helped Participant\_16 stabilise his mood swings and side effects. This shows that receiving information could help coping with side effects:

*"Well, if it wasn't for... Willow nurses, and Pine Centre... Pft... didn't know what was going on, what was happening. He was completely different. I didn't know him, my children didn't know him. And if it wasn't for them, explaining what he's going through and all that, I don't think we'd be sitting here together now. I don't know, and we were together 40 odd years."* **(Companion\_16 – Participant\_16's wife)**

### **8.2.2.3 Information can help cope with cancer treatment related side effects**

Some participants mentioned positive examples of information provision, which helped them cope with cancer related symptoms and treatment side effects. Participant\_02 explained that receiving information about side effects and how to cope with them before and during her chemotherapy treatment helped her cope easier.

*"I don't know really exactly what causes it [inaudible], but your throat closes up and you can't breathe and you can't speak and then luckily I was told beforehand that this could happen, so I knew what to do, so that was ok. it was very very frightening, especially if you didn't know what was happening, it would be terrifying."* **(Participant\_02 – person affected by colorectal cancer)**

Participants\_09 also mentioned that knowing what to expect helped him prepare and when certain side effects did not present, he was relieved.

*“Mood changes. I can sometimes get down and a little bit depressed and tearful sometimes, but I was told about this prior to having these injections, so I can find my way out the other side so to speak...” (Participant\_09 – person affected by prostate cancer)*

*“I was very fortunate for example with my radiotherapy, they did say that one of the side effects for that it might have some leakage or passing water etc. etc. I didn’t have anything. You know if I did, it was very very little. Whereas, some people it’s quite a problem. So, I was aware of it, then I was waiting for it to happen, but when it didn’t happen I thought ‘Oh, great’, so that hasn’t affected me.” (Participant\_09 – person affected by prostate cancer)*

Participant\_29 mentioned a positive example of information provision. He attended an information event in the hospital where the Fern Therapy Team is located. He recalled how hearing from an expert patient benefitted him:

*“[...] There was one guy who had had... has prostate cancer, [...] his input was amazing, because it’s one thing to understand things clinically and it’s another thing to live it and experience it. [...] I spoke to him one to one afterwards, and the level of information that came from him was really good.” (Participant\_29 – person affected by prostate cancer)*

Professional\_01 articulated that based on her studies, testimonials can be an effective way to provide information and get people ready for rehabilitation or help them change behaviour to a healthier lifestyle. This supports that having expert patients on educational and information events can be really beneficial.

*“If you use testimonials it makes it... Cos if you’ve seen actor on a telly ‘oh, it will never be been’ ‘I’m not gonna get lung cancer by smoking’ ‘It’s never gonna be me why, I’m not gonna change’ If you see someone who goes ‘I thought it was never gonna be me and look at me now’ that they’re gonna listen to more.” (Professional\_01 – OT)*

#### **8.2.2.4 Summarising information provision to increase people’s knowledge about cancer treatment related side effects**

These findings indicate that receiving written information is not necessarily enough or appropriate for everyone to help people understand their condition and where they could get support. Healthcare professionals might need to allocate time to communicate long-term and late effects more effectively, and to help people find timely support with their rehabilitation needs. These findings suggest that information both on available services and side effects need to be communicated in a way that is acceptable for the person, whether it is through education classes, one-on-one consultations, or written information. Healthcare professionals also need to make sure that the quality of information is sufficient for the person’s needs, and not too technical to understand. To understand what causes the issues



with raising awareness on rehabilitation services and side effects of treatments, the contexts that impeded information provision need to be explored.

### 8.3 Context – People’s perceptions, the wider MDT’s knowledge, medical model, lack of routinely provided cancer rehabilitation services, and lack of time

In the IPT it was theorised that people’s perception could be the context that influences raising awareness and eventually the uptake of services. If people had initial prejudices towards rehabilitation, they would not want to attend the services even though they have the information on what rehabilitation services to access. However, based on the interviews with people affected by cancer, the issue was not their perception of rehabilitation, rather than healthcare professionals’ not providing the right information at the right time. First, people’s perception is discussed and how this did not seem to be a context among the participants of this PhD study. Then, other potential contexts are discussed based on the interview findings.

#### 8.3.1 People’s perception of and attitudes towards cancer rehabilitation

People affected by cancer perceived the term rehabilitation mainly as aftercare, although a few of them indicated that receiving support as soon as their need arisen would have been helpful. As seen above, Participant\_10 and Companion\_16 were particularly articulate about their need for early rehabilitation input. Participant\_10’s attitude towards attending cancer rehabilitation was particularly surprising, as he had negative experience with hydrotherapy as musculoskeletal rehabilitation for his knee issues before. Therefore, it was expected he might not want to try the Willow hydrotherapy again.

*“I’ve had hydrotherapy [musculoskeletal] in Welsh town. And frankly that was a waste of time. As far as I’m concerned. It may have helped me a little bit physically, but not much. [...] the hydrotherapy [musculoskeletal] in Welsh town is more of a chore, isn’t it? You know, something that we thought ‘Let’s get in and get over with and...’ Totally different attitude.”*  
**(Participant\_10 – person affected by prostate cancer)**

Regardless of his previous negative experiences, Participant\_10 still tried the exercise classes run by the Willow Therapy Team.

In addition, an OT and a SLT highlighted that people affected by cancer do not necessarily call their work rehabilitation. Care provided by rehabilitation therapists are often referred to as “support” or “help with my cancer”.

*“[...] if you’d say ‘we are just helping you to live with what you’ve got’ that’s how they see it. They don’t always... we don’t always call it rehab. We’re just rehab therapists.”*  
**(Professional\_01 – OT)**

*“I’m not sure they use the word rehab. Which is quite interesting. I think they just use it as cancer support or help with my cancer.”* **(Professional\_02 – SLT)**

Moreover, Participant\_21 did not consider acupuncture as rehabilitation. She expressed that in her opinion it was more maintenance.

*“I think definitely with the counselling that is rehabilitation, I think the acupuncture is more management of ongoing symptoms rather than a rehabilitation, because hm... I’m on the Tamoxifen tablets now for 10 years, so that could potentially be a long-term thing.”*  
**(Participant\_21 – person affected by cancer)**

Maintenance is often considered to be part of cancer rehabilitation (Dietz 1974) as Professional\_01 described:

*“Rehabilitation from a therapy point of view hm... typically means restoring something. But when working from a cancer point of view is not always restoring, so you’ve got different alias [inaudible] of it. So you’ve got the preventative stuff, the restorative, the maintenance, and the... almost the palliative, so it’s more like a fourth [inaudible] phase approach to it depending on what actually is happening with the person at the time,...”* **(Professional\_01 – OT)**

Another interesting finding regarding perception was that people affected by cancer were often not aware of the profession of the AHPs providing care. Many participants referred to AHPs as nurses.

*“The Willow nurse has been brilliant, I do go to Tai Chi with them and tryna get my muscles back and other things...”* **(Participant\_02 – person affected by colorectal cancer)**

*“Then I was recommended to go to the gym in Yew Hospital with the Willow nurses.”*  
**(Participant\_16 – person affected by prostate cancer)**

Some people were aware that among the professionals leading the exercise classes there were physiotherapists. Participant\_03, for example, was aware that the Willow Therapy Team had physiotherapists, although she seemed to be oblivious that OTs were part of the team.

**“Researcher:** Do you know the professions of... of them, so what sort of?

**Participant\_03:** *They’re physiotherapists. Yeah. So they... Haha [laughing] try to get you going again...”*

However, the lack of knowledge of professional roles did not seem to majorly hold people back from attending the rehabilitation services.

Regarding perceptions of and attitudes to cancer rehabilitation, as the majority of participants attended exercise classes, attitudes towards exercise must be mentioned. It was presented in chapter 3, that having experience with exercise usually facilitated people accessing exercise-based cancer rehabilitation, while the lack of enjoyment in physical activity and attitudes, like “not being a sporty type” acted as barriers. In this study, many of the participants articulated that they had an active lifestyle prior to their cancer diagnosis or participated in sport when they were younger.

*“Well, I also started... after each Wednesday session, we do just... ¾ on a circuits training and from being an incredibly fit person I suddenly was doing a little bit, ‘well I really do need this, you know I’m supposed to be one of the super people’.” (Participant\_01 – person affected by prostate cancer)*

*“Before I was ill, I was going swimming three times a week and doing fifty lengths, although I’m an old lady.” (Participant\_02 – person affected by colorectal cancer)*

*“Because through the years I’ve done sport. I mean I did rugby in school, hm... I did karate for 25 years, I took my sons through it, you know, I’ve done sports all my life, so you can imagine how much I really enjoy the gym [circuits classes]”<sup>7</sup>. (Participant\_16 – person affected by prostate cancer)*

However, there was one participant who attended the exercise classes of the Willow Therapy Team without having a sporty background.

*“I was petrified of the gym. I had never been in... in a gym in my life and hm... I said to the Willow girls ‘Oh, no, I can’t stand it. I... I can’t... Those machines, they’re like torture machines.’ But they got me in there, slowly, but surely. I’ve used them all. They’re not torture at all. Hahaha [laughing].” (Participant\_28 – person affected by breast cancer)*

Participant\_28 had attended hydrotherapy and circuits classes regardless of her initial perception. Therefore, people’s perception and attitudes towards exercise might not be a context that inhibited access to cancer rehabilitation. However, as only people who attended cancer rehabilitation services were interviewed, it is possible that people who did

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<sup>7</sup> People affected by cancer often referred to the circuits classes as gym or Willow gym.

not access the cancer rehabilitation services or disengaged early had a less supportive perception of physical activity and exercise.

### 8.3.2 Wider MDT's perception and knowledge and the medical model

As seen above, people's perception and attitudes towards cancer rehabilitation did not necessarily affect service uptake. Based on interview data what seemed to be a bigger issue was the knowledge and perception of the wider MDT. This led to the lack of consistency in mode people learnt about cancer rehabilitation services. Referral from nurses, third sector services, and education courses were among the many ways in which people found out about cancer rehabilitation at Willow and Fern. It seemed that people often learnt about cancer rehabilitation from sources outside of their cancer treatment centre where the therapy teams were located. A possible context for this could be the wider MDT's knowledge and perception of cancer rehabilitation. Healthcare professionals interviewed for this study reported that doctors and sometimes nurses often considered rehabilitation as an extra or an add-on; therefore, they did not necessarily refer to the services.

*"I think we're seen as an add-on, where is actually if we were utilised earlier, they actually, we're not an add-on, we can actually enhance the services and enhance the quality of care. Hm... but that's not always seen until the end, yeah."* **(Professional\_06 – physiotherapist)**

*"I'd like to see a... a therapies team as a whole embedded into strategies, embedded into discussions, it being not seen as an adjunct or an extra, but as a core hm... service. Hm... so I would like to see the recognition."* **(Professional\_09 – SLT)**

Some of these perceptual issues stemmed from the ever present medical model in healthcare, that treatment interventions affecting the cancer had higher priority than treatment related side effects.

*"Is this very much a focus isn't it on 'This is your treatment, you're gonna have radiotherapy, you're gonna have chemotherapy.' And I think sometimes yeah, they don't see the holistic picture and the bigger picture and actually how they can support patients through that. Because actually if we were involved sooner with their patients, they would get through the treatment easier. And I think there's certainly a medical model and culture yeah. Which is frustrating, but yeah, I certainly think that it's that kind of nurses and doctors, and you know everyone thinks it's just nurses and doctors in the NHS."* **(Professional\_06 – physiotherapist)**

*"What change would I like to see? I would like to see better recognition of holistic therapies as a whole. So I would like a much less medic centred culture, I'd like more awareness of the whole person and their wide reaching needs as opposed to just focusing on treatment..."* **(Professional\_09 – SLT)**

*"I think the culture within the NHS, because it's very focused on nurses and doctors that has to change."* **(Professional\_18 – dietitian)**

*"[...] so we have a big challenge on our hands to encourage the wider multidisciplinary team to stop thinking about that medical model and start thinking more about the long-term conditions model, which is more multidisciplinary and supporting people to look after themselves in the long run."* **(Professional\_14 – OT)**

However, Professional\_14 added that there are MDT professionals who are open to include cancer rehabilitation and therapies in their treatment pathway.

*"[...] it's like all things you know we make so many generalisation, don't we about all you know everybody thinks medical model, we know that there are clearly medical professionals out there who are very supportive of therapies and will imbed therapies early in their pathways."* **(Professional\_14 – OT)**

Professional\_19 agreed that there were professionals in the wider MDT who were supportive of cancer rehabilitation, adding that historical good relationships with certain teams was a facilitator. However, where relationship was not built between AHPs and MDTs, a lack of respect towards the AHPs was perceived:

*"From an oncology perspective it's very smooth, I think historically we've always like got on very well with the doctors, we built up a good rapport, I think they respect us as therapists. Which is a big thing, I think we've worked quite hard for that so that's always been quite smooth... From a haematology point of view, because they're not always based on the ward and I think it always leads from the higher... the consultants. If their understanding and respect isn't there, then it doesn't follow down, so haematology wise it's not so smooth..."* **(Professional\_19 – physiotherapist)**

Moreover, knowledge issues of the wider MDT regarding cancer rehabilitation affected their ability to refer to services. The wider MDT did not know that services existed within their local hospital.

*"I did a questionnaire for consultants last July, we did a questionnaire for outpatients last autumn, 66% of outpatients didn't know Therapies were in Fern, which is shocking."* **(Professional\_13 – SLT)**

*"I guess we're asking for medical and nursing colleagues who are involved in that very early stage, we're asking them to talk about services that they might not even know exist. So there's a lack of awareness of what cancer rehabilitation services are available. [...] We're also asking them to prioritise rehabilitation. So, if there's a lack of awareness it would be easiest and... they don't understand what we do, then we're not going to feature as a priority above all of the other biomedical stuff."* **(Professional\_14 – OT)**

Professional\_02 mentioned that if the MDT does not know what certain AHPs do within the cancer centre, then AHPs cannot expect people affected by cancer to know.

*“[...] if the staff don’t understand, how would you then expect a patient who’s maybe never come across a speech therapist to understand [...]” (Professional\_02 – SLT)*

*“I think unfortunately we have quite a... a quiet reputation, not everybody knows what we do as a Therapies Team let alone then the breakdown of physio, OT, speech and language [...] but they still unfortunately I think even this to this day a lot of doctors don’t realise what we’re here for and what we can do for the patients.” (Professional\_05 - Therapy technician)*

These issues with information provision on available rehabilitation services may have led to the fluctuation in uptake at the Willow Therapy Team over the years. In addition, the findings of the secondary analysis were discussed with the Steering group of this realist evaluation. As two of the original members of the Willow Therapy Team were involved in the Steering group, they were a reliable source on what could have caused changing patterns of uptake. Regarding the overall drop in cases in 2017 and the drop in breast cancer cases, the Steering group members mentioned that a physiotherapist in the Team went on maternity leave in March 2017. She worked as a contact to other services, such as the lymphoedema team. After the physiotherapist left, other services involved with people affected by breast cancer stopped referring, as they thought others in the therapy team could not provide the same rehabilitation interventions as the physiotherapist. Insufficient knowledge among the wider healthcare community on cancer rehabilitation services available and AHP competencies led to the drop in cases in 2017, indicating that education and service promotion for the wider healthcare community might be necessary to optimise the uptake of cancer rehabilitation. The staff numbers obtained from the Willow Therapy Team from 2014 until 2017 showing maternity leave can be found in Appendix 24.

In addition, historical issues with therapy team organisation have led to lack of referrals and rehabilitation service uptake. Professional\_13 described how AHPs attached themselves to clinics where they found the greatest health needs relevant to their profile. Therefore, other clinics did not know they existed within the hospital or that they could have been an asset to their teams.

*“[...] we’ve historically delivered services here is we’ve attached ourselves to a couple of teams who have been needed most and closed off referrals to the general... to all patients [...] I think historically it was the case of managing need, so they prioritised those clinics that had the most needs, so dietetics were upper GI and head and neck. Speech therapy was predominantly head and neck with some neuro. I think they just felt that ‘Oh we’ve got a high profile there, we’ll stay there’ without appreciating the bigger picture of what about all those other patients and actually you almost need to work with some of those smaller sites to show just how useful you are until you work in those...” (Professional\_13 – SLT)*

In support of Professional\_13's account, dietitians and SLTs felt respected in their roles as specialists in certain cancer sites:

*"There is differences though, so in Fern I know that with certain consultants and specialist nurses and things they value your role a lot more than others do. So yeah, there is variance even in... within oncology, but I think if you pick, compare oncology to other areas then it's a lot better, and if you compare... where I'm working at the moment, I'm with the head and neck team and it's a lot better to other areas of oncology."* (Professional\_17 – dietitian)

However, outside of head and neck cancer, some dietitians felt that they were not equal to other therapies, implying physical health and performance of activities of daily living is always more important than eating.

*"I think of the AHPs when times are hard with the NHS, you know money, resources, we would be the ones that kind of put a little bit of the back... on the back-burner, because it's more important that somebody can use the toilet or walk up and down the stairs than it is if they can eat their dinner or not, as sad as that sounds, but I think that's always, well that has been the case."* (Professional\_04 – dietitian)

This was supported by an account from Professional\_12, who mentioned that the physiotherapy team was always well funded.

*"I think the phys... well the physio team are... they're actually undergoing massive changes at the moment, and whereas historically they've always been the most well-resourced team, [...]"* (Professional\_12 – OT)

Due to the above-mentioned issues with the wider MDTs' knowledge and perception on cancer rehabilitation and AHPs, service promotion beyond the wider MDT is important. Professional\_19 highlighted that providing an education session for a haematology department in their local hospital helped increase the knowledge of the haematology staff and the number of referrals.

*"[...] Therapist\_03 did a... in-service training with them to explain what our team is, what we do and what cancer rehab is. So we've had a lot more referrals since then and that was only a month ago."* (Professional\_19 – physiotherapist)

In addition, Professional\_01 mentioned that working closely with nurses and the wider MDT gradually helped changing perceptions on the oncology ward.

*"Some of the older ones [doctors] are still traditional doctor model potentially and that's not just doctors. Some of our older therapists, some of our older nurses... It's just the culture... and what they've seen. It's like when we're first started doing rehab with patients on the ward. It's like 'why are you doing that, that's really cruel?' and I 'Well, why shouldn't*

*they live well?’ And this is how they’re going to live well. That’s never questioned and never challenged anymore.” (Professional\_01 – OT)*

AHPs need to take an active role in promoting their role in cancer rehabilitation to facilitate referrals to their services and uptake.

### 8.3.3 Lack of consensus on what cancer rehabilitation means

A possible reason for the perception issues regarding cancer rehabilitation could be that there is no consensus about what rehabilitation means. The 20 healthcare professionals interviewed gave various responses regarding what rehabilitation meant to them. Many AHPs articulated that rehabilitation was all-encompassing, providing input from diagnosis until the end-of-life:

*“I see cancer rehabilitation as encompassing at any... at being utilised at any part of a... the patient’s cancer journey, so that could be right at the very onset, at diagnosis, right through to end-of-life.” (Professional\_12 – OT)*

*“It’s [cancer rehabilitation] quite an all-encompassing term I suppose. It can be you know... it could be nutrition, it could be physical stuff, it could be emotionally but it’s about actually I suppose establishing what the patients’ needs are and then supporting them to maximise their ability hm... to enable them to do what they want to be able to do.” (Professional\_06 – physiotherapist)*

However, a few dietitians from Fern Therapy Team did not feel like what they provided was rehabilitation. They considered rehabilitation as aftercare.

*“For our profession specifically it’s [cancer rehabilitation] not something that we’re really involved with however, I think that’s there is scope for change, so I’d like to think that you know dietitians could be more involved in the rehabilitation side of it but obviously I do think that rehabilitation is imperative for a lot of patients ongoing you know, cos they might be discharged from Fern, they have many many year of concerns afterwards so yes.” (Professional\_07 – dietitian)*

This perception was the result of the hospital organisation, as the hospital where the Fern Therapy Team is located mainly provides treatments and people are referred back to their local university health boards when treatments end. Therefore, dietitians need to discharge people to their local teams:

*“I think just cos you survive cancer doesn’t necessarily mean you’ve got a good quality of life afterwards and I think that’s kind of the most important thing for people. I think that’s something we don’t focus on enough or we don’t... consider enough really. Especially here at the moment, we’re a treatment centre, so our focus is very much on getting them through the treatment as opposed to the after bit. Kind of transfer them back to the local*



*hospital and you know it's their problem to deal with, but I suppose it's probably something we should be addressing kind of it, day one almost.” (Professional\_04 – dietitian)*

SLTs described cancer rehabilitation as a “fuzzy word”, as people affected by cancer cannot necessarily be rehabilitated in a traditional sense. Traditional rehabilitation was considered as recovery, which might not be achievable for every person affected by cancer.

*“So, I’m in a bit of a quandary by the word... word rehabilitation, I don’t know if it’s a bit outdated in a way, to be honest, because it keeps people, certain people in a mind-set that if it’s not gonna get better, it’s not worth doing, and I don’t think that’s particularly healthy attitude to have, which is funny enough, probably the old attitude, not that I didn’t use to invest in people, cos I used to work with progressive neurological conditions, but in my head rehabilitation was, you know someone who had a stroke, you gave them a little bit of language input and they were better again. It’s not like that at all anymore; it’s very sort of fuzzy, fuzzy word. So, I think that’s what it means to me. It means a fuzzy word. Hahaha [laughing]” (Professional\_09 – SLT)*

*“I think it depends on in my head the term changes depending on what the... where the location of the cancer is. [...] I think rehab within seeing the head and neck population is kinda getting them through their treatment, [...] And then 40% of our case load is kind of the neuro-oncology. And I think our rehab with them is bit different. So, we can support with palliation and end-of-life kind of care. We can actually do traditional rehabilitation and therapy if they’re in the position to want to improve a certain area.” (Professional\_02 – SLT)*

*“Rehabilitation from a therapy point of view typically means restoring something. But when working from a cancer point of view is not always restoring, so you’ve got different alias [inaudible] of it. So you’ve got the preventative stuff, the restorative, the maintenance, and the... almost the palliative, so it’s more like a fourth [inaudible] phase approach to it depending on what actually is happening with the person at the time, [...]” (Professional\_01 – OT)*

This lack of consensus on what cancer rehabilitation means among the AHP community could lead to perception issues in the wider MDT.

*“What does it mean to me? This is probably part of the reason why it’s so hard to have our... have our colleagues understand this, because cancer rehabilitation is so broad.” (Professional\_14 – OT)*

#### 8.3.4 Cancer rehabilitation is not routinely provided in the cancer pathway

A context that largely influences uptake and information provision about available services is that cancer rehabilitation is not routinely provided within the cancer pathway.

*“Referrals into us is probably the other big difficulty, is quite ad hoc, it’s only when people know about us, so it’s not routine within pathways that if you’ve got a cancer diagnosis you get the opportunity to see a therapist.” (Professional\_01 – OT)*

If cancer rehabilitation was routinely provided, people would see a rehabilitation professional throughout the cancer pathway and AHPs would not need to rely on the wider MDT to provide information for people affected by cancer or refer to the services. In addition, the lack of routine cancer rehabilitation provision leads to fragmented services, as some hospitals might employ rehabilitation professionals with experience in oncology, while others might only provide generic rehabilitation services, which often has to prioritise other conditions and health issues, such as fall prevention, stroke rehabilitation, or musculoskeletal issues.

*“If they become even lower performance status, we have like the resource teams and things where they’ve got therapists, but they’re not cancer specialists. They’re non-cancer, well they’re non-specialists, they don’t have a specific... they just... they work in the community regardless of a diagnosis of anything. They hm... they are also a time limited service and often have all the pressures on them, so it might be one month they’ve got to focus on falls and the next day they have to work on hospital admission prevention or getting people out of hospital, so their agenda and what has been... the pressures that are put on them are changing all the time.” (Professional\_01 – OT)*

*“Neuro is a bit more haphazard. So, they might have their treatment in say, their surgical treatment in Birch Hospital. So, they get transferred from their local team to Birch Hospital. Birch Hospital then transfer back out to the local team, cos it might be a few weeks before they come here, they might not come here. And the teams locally are a bit more haphazard,...” (Professional\_02 – SLT)*

This could lead to a loss of continuity of care if people are transferred from one hospital to another.

However, SLTs and dietitians working in head and neck cancer mentioned that their cancer pathways are fairly smooth and straightforward.

*“So head and neck has got a very clear pathway. There’s a national pathway you [inaudible] can follow yeah, very strict, very rigid.” (Professional\_02)*

Moreover, Professional\_14 mentioned that thanks to continuous service promotion efforts, cancer rehabilitation is slowly being embedded into the cancer pathway. However, she noted that improving awareness and changing culture is challenging.

*“Now it’s something that is slowly being imbedded into some of the pathway work that’s being done. It’s being promoted as part of the multidisciplinary offer. It is being supported by a wider range of people. And I think we are sharing the message in as many places as we can. And I think that’s... one of the challenges is trying to change awareness and culture.” (Professional\_14)*

### 8.3.5 Time to provide information as a barrier to information provision on cancer treatment related side effects

Regarding information provision on late and long-term effects, many participants mentioned that healthcare professionals, mainly the wider MDT, including oncologists, radiographers, and in some cases nurses, often did not have enough time to talk to them about side effects:

*"You don't really want to ask trivial questions. I mean obviously if there's something important, you would say, but I've never seen any of them sit down, I've never once seen one of them able to just sit down, other than d... just on the go constantly. And then they discuss sometimes it's 2 o'clock and they have... they haven't had lunch or anything you know and... it's not easy. Sooo... communication is not always as it should be I feel in a perfect world. BUT I understand how it can't be as well at the same time, yeah?"*  
**(Participant\_02 – person affected by colorectal cancer)**

*"A lot of nurses, you know on the wards or anything like that, they're just so busy, they can't be bothered. They haven't got time."* **(Participant\_10)**

Companion\_16 highlighted that the MDTs lack of time could be a potential barrier to information provision.

*"If it wasn't for some of the... the meetings and the chats we had in Pine Centre, well we haven't got a clue, cos nobody seems to... have time to sit down and talk and explain everything 'Now, this is what's gonna happen, this is what he's gonna go through. This is how he's going to change.' I don't think the doctors in there realise exactly how different they are... Or whoever it is who has the cancer."* **(Companion\_16 – Participant\_16's wife)**

People affected by cancer in many cases only received written information about side effects, but as seen above, in the mechanisms section, leaflets and booklets were often insufficient and could lead to further anxiety. Healthcare workers need to ensure that information provision is personalised, and people affected by cancer can have a choice between written information or in person talk about possible side effects. As cancer services are often overwhelmed by new cases, employing rehabilitation professionals right from diagnosis could help take burden of the wider MDT regarding information provision, and could help ease people's anxiety with timely information on side effects and support services.

### 8.3.6 Communication issues between people affected by cancer and the wider MDT

Participant\_12 mentioned that he experienced communication breakdown between him and his oncology MDT. He said that he felt like some healthcare professionals thought people know everything. This could be a potential barrier to information provision.

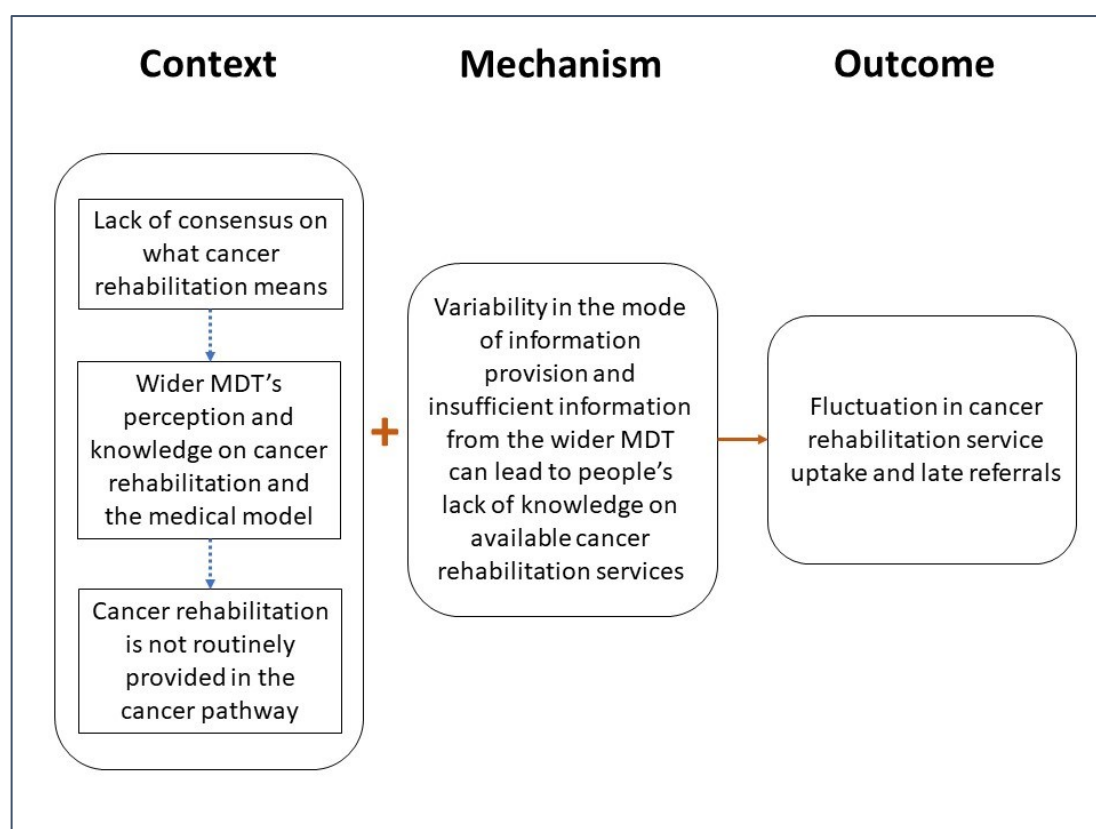
*“It’s a training thing, it’s a communication thing and it’s people... I think the urologist or... or the doctor, or the oncologist even when they say to you ‘This is what you’ve got’ I think they think we know all about it. Well, we don’t. We just don’t know. And you don’t know what it’s like walking into a fog, and your first impression was ‘Why me?’ it’s... that’s what’s what people say.” (Participant\_12 – person affected by prostate cancer)*

## 8.4 Refined CMO\_1

Originally, the IPT suggested that information provision will result in increased cancer rehabilitation uptake if people’s perception and attitudes were supportive of cancer rehabilitation. However, the findings showed that uptake of both the Willow and Fern Therapy Team often fluctuated. Interviews with people affected by cancer showed that issues existed with the provision of information on available cancer rehabilitation services. The interviewed participants often reported that they would have accessed cancer rehabilitation services if they received information earlier. The perception and attitude of people affected by cancer did not seem to be a context that inhibited uptake and information provision. However, as mentioned above, the majority of interviewed participants had an active lifestyles prior to their cancer diagnosis, which might be a supportive context.

What seemed to inhibit the mechanism of information provision and raising awareness was the wider MDT’s perception, and insufficient knowledge, and the medical culture. These perceptual and cultural issues might be exacerbated by the lack of consensus among AHPs on what cancer rehabilitation means. Moreover, cancer rehabilitation is not routinely provided in the cancer pathway, meaning people will not necessarily see a rehabilitation professional unless they are referred to their services by other members of the wider MDT. However, the wider MDT’s perception and knowledge could influence the cancer pathway, and the routine provision of cancer rehabilitation. This potential association is depicted on Figure 13 which shows the refined CMO\_1.

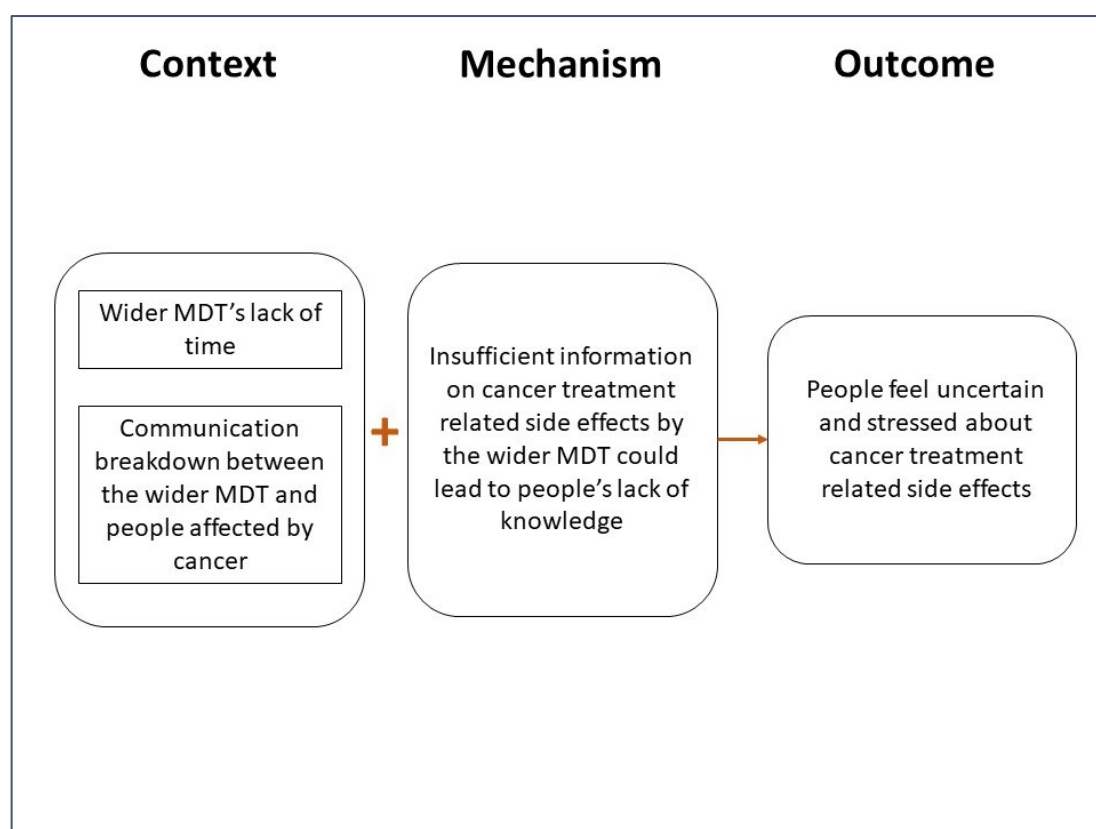
Figure 13 Refined CMO\_1



Healthcare professionals interviewed for this PhD study suggested that education of the wider MDT could facilitate cultural change and increase knowledge about cancer rehabilitation within the MDT. Facilitating cultural change could help making cancer rehabilitation routine in the cancer pathway.

Moreover, information provision is important, not only to raise people's awareness and knowledge on available services, but on cancer treatment related side effects. People affected by cancer interviewed for this PhD study reported that they often did not receive information about side effects, or if they did, the information they received was insufficient, such as inadequate written information. These often led to uncertainty and added stress for people affected by cancer, who did not know which side effects were normal and what to expect. The reason for the insufficient information was the wider MDTs lack of time to talk to people, and potential breakdown of communication. The resulting alternative CMO\_1 is presented in Figure 14.

Figure 14 Alternative CMO\_1 regarding information provision



Potential solution for this insufficient information provision regarding cancer treatment related side effects could be earlier referrals to cancer rehabilitation and potentially, to third sector support services. Those people affected by cancer who had sufficient knowledge on potential cancer treatment related side effects were able to prepare and cope better.

## 8.5 Conclusion

This chapter introduced the findings of the quantitative and qualitative data analysis, by testing and refining IPT\_1. IPT\_1 hypothesized that information provision on available cancer rehabilitation services can facilitate service uptake of people affected by cancer if people's perceptions and attitudes are supportive. However, findings indicate that information provision is often insufficient, resulting in the fluctuation in the uptake of cancer rehabilitation services. The contexts influencing information provision were the wider MDT's perception and insufficient knowledge of cancer rehabilitation, and the medical model. Moreover, cancer rehabilitation was not routinely provided which also negatively affected information provision. Additionally, an alternative CMO\_1 was created,

as people affected by cancer in the study often reported little or insufficient information received regarding their treatment related side effects. This caused distress for people affected by cancer, who suggested that earlier access to cancer rehabilitation could have helped them prepare for and cope with cancer treatment related side effects. The next chapter introduces the findings related to IPT\_2, which considers healthcare professionals' training needs assessment and training.

## Chapter 9: Healthcare professionals' training, professional boundaries, and the vicious cycle of time and staff

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This chapter presents the findings of the analysis related to IPT\_2, which was introduced in chapter 4. First it is considered if the IPT worked or not by investigating if the outcomes are in line with the IPT. Then mechanism and contexts discussed. Finally, the chapter introduces the modified new CMO\_2. The second IPT aims to explore how training healthcare professionals to provide cancer rehabilitation services works in South Wales. The IPT\_2 is presented below, for ease:

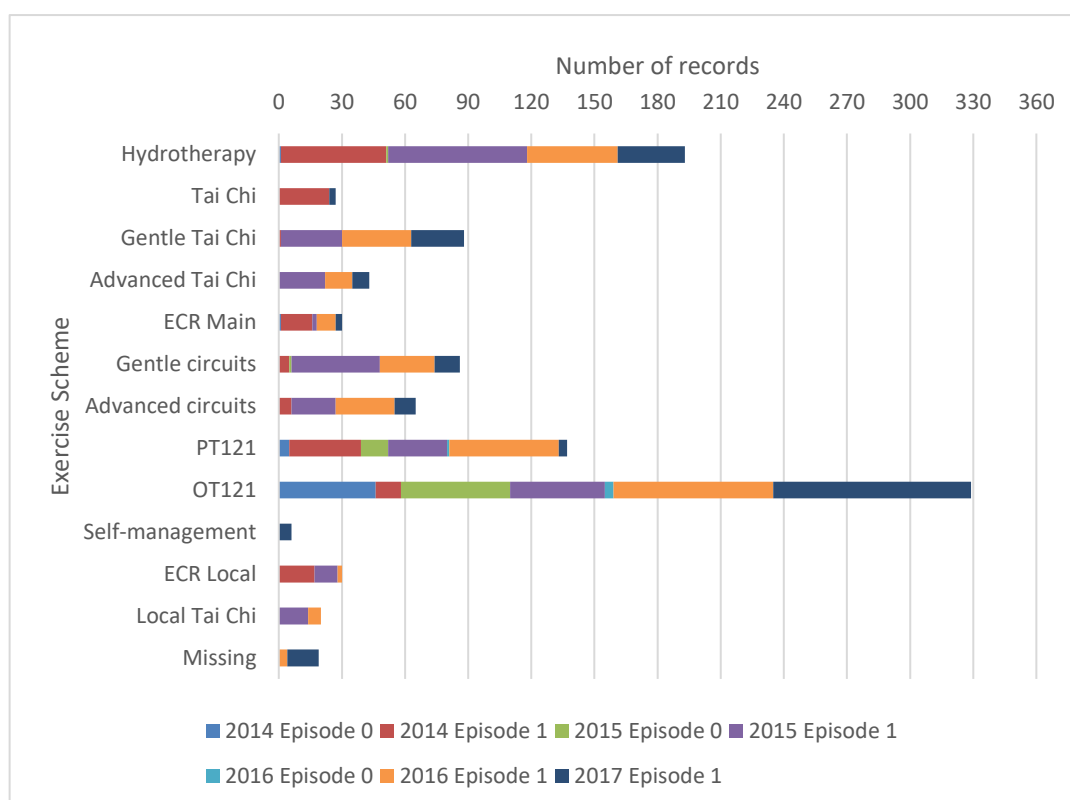
IPT\_2: To provide appropriate range and volume of rehabilitation services (**outcome**) that can meet the needs of people affected by cancer, healthcare professionals' training needs should be frequently assessed, and training should be provided (**mechanism**). Training availability is influenced by the level at which healthcare professionals work at based on the four level model (**context**) (NICE 2004, Welsh Assembly Government 2010).

### 9.1 Outcome – Range and volume of rehabilitation services

The routinely collected data by the Willow Therapy Team can provide information on how the range and volume of services changed over the years. The database acquired from the Willow Therapy Team contained data on the exercise classes people affected by cancer attended. Episodes 0 and 1 are depicted on Figure 15 as these two episodes show all the exercise schemes people could have enrolled at the Willow Therapy Team over the years. Later episodes were only continuation of exercise schemes that people started in episode 1.



Figure 15 Number of records for each scheme in episodes 0 and 1 over the years



There were fluctuations in the number of people who attended the exercise classes over the years. Some of these fluctuations were the result of the uptake changes discussed in the previous section. One-to-one OT sessions (OT121) had the highest number of records over the years because people who did not attend or only attended assessments in episodes 0 and 1 were booked as OT121. Hydrotherapy was the most popular intervention in 2014 (n=50 in episode 1) and 2015 (n=66 in episode 1), although from 2016 (n=43 in episode 1) the number of people attending hydrotherapy gradually decreased. On the contrary, attendance in gentle Tai Chi, advanced circuits, one-to-one physiotherapy sessions (PT121) and OT121 increased in 2016 compared to 2015. However, apart from OT121, the number of records dropped in every exercise class in 2017.

In 2017, only four records were labelled with PT121, compared to 52 (episode 1, 2016), 28 (episode 1, 2015), and 34 (episode 1, 2014) in previous years. The reason for this was that only OTs worked in the outpatient service from March 2017 as the physiotherapist was on maternity leave and could not be replaced. Staff numbers from 2014 to 2017 can be found in Appendix 24. Moreover, some exercise classes disappeared by 2017. Enhanced Cancer Recovery (ECR) was an education course run by the Willow Therapy Team. Main and local

referred to the location of the courses. Main was provided where the hospital the Willow Therapy Team resided in while local referred to another hospital approximately 20 miles from the Willow Therapy Team. ECR Main was stopped as this service was gradually replaced by the circuits classes. Gentle and advanced circuits classes were developed in 2014. Regarding ECR Local, a healthcare professional from the Willow Therapy Team had to travel to this local hospital to provide cancer rehabilitation for people closer to their home. In addition, Tai Chi sessions were also held in the locality. However, due to staff shortages and travel issues, the Willow Therapy Team had to discontinue the local exercise classes in 2017.

Other changes over the years included adding new services. Tai Chi classes were split into two classes in 2015 to meet the needs of more people affected by cancer and to allow easier tailoring of the exercise classes. The two classes were named gentle and advanced Tai Chi. In 2017 there were cases reported as “Tai Chi”, although these were typing errors. A new self-management scheme was started in 2017. Self-management meant that people affected by cancer attended the initial assessment and they decided to exercise on their own, without attending the Willow exercise classes. Healthcare professionals only had an assistive and monitoring role throughout self-management.

In summary, while the development of two Tai Chi and two circuits classes indicated that the Willow Therapy Team could provide extensive services, cancelling some exercise classes in the other locality implies that providing a wide range and volume of cancer rehabilitation services was challenging. In addition, the reduction in PT121 in 2017 suggests that in order to provide a wide range and volume of cancer rehabilitation services, adequate staff numbers were needed. Staff capacity and range and volume of services are closely linked, as seen in the case of PT121, if no physiotherapist is employed in a team, no physiotherapy services can be offered. Therefore, staff capacity and range and volume of cancer rehabilitation services cannot be separated and are discussed as one outcome for this CMO.

The qualitative interviews support that providing a wide range and volume of rehabilitation services was difficult. almost every healthcare professional interviewed reported that staff capacity was a major issue. Many AHPs were providing the bare minimum of services, or had to prioritise tasks due to insufficient staff numbers.

*“You know three [dietitians] for the whole of Fern is not really adequate in terms of safe caseloads and services you’d like to provide, you’re kind of doing a bit more of a firefighting*

*services as opposed to a proactive and a service that looks at the entire pathway. I think we just focus on treatment; we don't look at all the different steps.” (Professional\_04 – dietitian)*

*“The main barriers really are time and staffing. I think that’s quite typical for most of us.” (Professional\_07 – dietitian)*

*“Staffing levels, like ideally we could see patients twice a day, maybe more if they need it. We do often have people who need quite intense rehab, especially our haematology patients that... they can come in quite weak, but often there’s only one therapist available, and if the ward is busy, there’s no chance of seeing them regularly.” (Professional\_19 – physiotherapist)*

Moreover, improving, and developing cancer rehabilitation services was impacted by staff capacity issues.

*“Been able to offer flexibility in timings as well would be another thing that would be beneficial and it would help people to attend, but again we’re quite limited because of our staffing and ability to cover classes.” (Professional\_15 – physiotherapist)*

*“So, I’d say time’s a big one. I’m... kind of services so as in staffing levels, so if we had potentially more members of staff, we’d be able to hm... develop our service in different localities, do more classes, you know have... different options I guess.” (Professional\_16 – OT)*

Besides the healthcare professionals, some people affected by cancer who were interviewed noticed that staff capacity was an issue. Participant\_09 said that exercise classes had to be cancelled, as the professionals leading the sessions had to help out on the inpatient ward as they were short of staff.

*“There have been some cutbacks in that hm... we have missed a couple of gym sessions, because they just couldn’t allocate time to them, because they had to go on the ward to help the... you know, the patient on the wards.” (Participant\_09 – person affected by prostate cancer)*

Two OTs, one from Fern and the other from Willow, were the only two professional groups who reported that they were either full capacity or just managed to recruit a new member of staff. In Fern, Professional\_12 reported that for the first time in a long time the OT team was on full capacity, which helped the team to start developing the site-specific therapy pathways.

*“For us as a service at the moment we’re actually finally fully staffed, I’m not holding any vacancies, so you know with reference to sort of the neuro-oncology service, my new band 6 OT that’s part-time, I’ve sort of handed that service over to her to come up with her own pathway, try and just standardise and formalise our processes, so that if another OT came*

*in or if I looked at it and I said right, this is the process we need to follow for these patients.”*  
**(Professional\_12 – OT)**

In the Willow Therapy Team, Professional\_20 reported that having a new member of staff on the inpatient ward enabled them to see new admissions before the ward round, ensuring that every person affected by cancer was seen on a timely basis.

*“I’ve been around about a year without a band 5 OT, so with it just being me, it’s been very much prioritising the ones that absolutely need OT input. What I’m keen to do is now that there’s two of us is... even before the morning ward round, which is at 9 o’ clock, getting out on the ward so that any new patient we have spoken to or certainly had the chance to kind of eyeball them, make sure ‘Hm... actually they... they look like they could need us’ and then disseminate the right sort of information, so it might be via an OT leaflet or a physio leaflet and just kind of get that from them even before ward round, so getting in there as early as possible...”* **(Professional\_20 – OT)**

Professional\_12’s and Professional\_20’s accounts support that having adequate staff numbers was needed for the provision of cancer rehabilitation services. However, another issue with the range and volume of cancer rehabilitation services was the availability of services in other localities. The Willow and Fern Therapy Teams often had to discharge people after their treatments ended in the cancer centres, particularly if people lived closer to other hospitals. However, discharging people was often difficult, due to a lack of rehabilitation services outside of Fern and Willow Therapy Teams that could support people affected by cancer.

*“We currently have quite a lot of West Wales laryngectomy patients still on our caseload, because they’re historic, because of there’s only been... only very very recently as in within the last five years that West... that [Welsh location] have been managing laryngectomy patients, so we have a lot of patients on our caseload that are from Welsh town, from [Welsh location] and further afield.”* **(Professional\_11 – SLT)**

*“I do feel particularly for the neuro patients, that it’s not really an option for us to discharge them. There’s not enough out there in the localities to provide that sort of ongoing monitoring, review process really and we’ve had a couple come through where we ended up on a Friday afternoon crisis managing them at home.”* **(Professional\_12 – OT)**

These qualitative interviews with healthcare professionals and the quantitative secondary analysis indicate that providing a wide range and volume of cancer rehabilitation services was not always possible. This implies that IPT\_2 might not work. Exploring the mechanisms and contexts can help understand what led to staff and service provision issues.

## 9.2 Mechanism – training needs assessment and training

It was theorised in IPT\_2, that having healthcare professionals training needs assessed and training provided based on that can help develop a range and volume of cancer rehabilitation services. As seen in the outcomes, cancer rehabilitation services are limited, manifesting in staff capacity issues and lack of cancer rehabilitation provided in hospitals outside of the Willow and Fern Therapy Teams. Therefore, the mechanisms behind these issues need to be further investigated. The qualitative interviews helped investigate the mechanisms of training needs assessment and training.

### 9.2.1 Training needs assessment and training to increase professionals knowledge

Based on the interviewed healthcare professionals' accounts, training needs were among service outcomes that the Fern Therapy Team had to report on to the hospital management, indicating that training needs assessment was taken seriously.

*"Everyone make sure we have our PADRs [Personal Appraisal and Development Review] annually, and our monthly training needs to be up to date." (Professional\_13 – SLT)*

In addition, training needs were often self-identified supported by discussions with management. However, depending on healthcare professionals' interests and the level of specialism, the difficulty of finding training varied. Some healthcare professionals reported that after they discussed their training needs with management, in-house training was organised by their respective Teams or hospital.

*"Wherever I could access training from an in-house perspective, or the CNSs [cancer nurse specialist] would do an in-service training for us on... oncolog... oncological emergencies and that sort of thing" (Professional\_12 – OT)*

*"we do kind of in-service training, hm... so we get speakers to come and talk to us about different topics. And that's kind of whatever's identified within the team. So, we can kind of identify learning needs and ask speakers from different areas to come and discuss that with us." (Professional\_15 – physiotherapist)*

*"I was able to seek out the training that was much more relevant for me. Some of that was done in-house, for example some of the communication courses were done by palliative care [...] it was very much decided with myself addressing my own learning needs and with my manager as to what courses were appropriate. A lot of them might... as I said were done... within the hospital or within... you know the locality or local Health Board." (Professional\_20 – OT)*

Professional\_11 mentioned that specialist cancer rehabilitation training exists, but professionals often need to move and switch jobs to receive it. Professional\_11 for example moved to another city to learn specialist skills, as she felt she could not have gained that knowledge in her local hospital in Wales. She later returned to Wales with highly specialist skills in diagnostics and swallowing assessment.

*"I knew I had to go, I was in [Welsh location] and I realised I wasn't gonna ge... get those... get that training and skills that I needed to progress my career and... and to progress as a speech therapist and clinician, so I made a decision to move to [English city], did that and it was brilliant, got upskilled hugely."* **(Professional\_11 – SLT)**

A few healthcare professionals who were interviewed were studying for a Masters degree. There is no cancer specific AHP Masters degree available, although healthcare professionals were able to choose modules that were focusing on oncology.

*"So, it's just for a band 7 they expect you to be working at a Masters level, so I've just completed that, I'm graduating in a couple of weeks. (giggling) So with that course it wasn't specifically oncology based, but you can do Masters in palliative care or some of my hm... AHP colleagues did. I didn't, I went down the dietetic route, make it more dieteticky rather than general palliative care, but within that I chose, I kind of focused it quite heavily on oncology."* **(Professional\_17 – dietitian)**

Moreover, some healthcare professionals expressed that they learnt a lot of their skills in less formal ways. Healthcare professionals' learning happened on the job, gaining experiences as they worked in oncology, and taking opportunities as they arose.

*"Then I got moved on to oncology just as a rotation. It was literally just from being here with experience I did a lot of courses, I took a lot of opportunities where I was able to do lots of work with the lymphedema team and learn that side of things. I was able to do lots of work with [Charity] and learn like specialist skills. But I haven't had any sort of formal cancer training, it's purely just from my experience..."* **(Professional\_19 – physiotherapist)**

Professional\_12 highlighted that attending MDT meetings aided her becoming a cancer specialist OT.

*"I think a lot of my learning came from attending multidisciplinary team meetings where sort of where medications were being talked about day in day out, so you actually got to learn about titration processes and that sort of thing."* **(Professional\_12 – OT)**

In addition, Professional\_18 expressed that peer learning was an important part of training. Professional\_18 mentioned that she often met with other AHP colleagues as sharing their experiences helped their learning. Moreover, she highlighted that colleagues do not

necessarily have to come from the same profession. Professional\_18 often met with physiotherapists.

*“Plus, we do peer learning with colleagues as well, so we’ve kind of got such a diverse... hm... one of my colleagues I meet up with is a physio background. So, she’s... you know she’s brilliant. It’s just like... we just bounce... and there’s a lot of things we all encounter, is... it doesn’t matter what profession you’re in, you have the same challenges. So that’s been a real eye opener. And the learning from each other and... that action learning sets that typically we do a lot of.” (Professional\_18 – dietitian)*

These accounts indicate that training and development to increase knowledge in cancer rehabilitation can happen in various ways for AHPs who want to specialise in oncology. However, Professional\_12 added that gaining oncology specific knowledge for junior staff can be challenging, and she needed to keep in mind how to pass on her knowledge to colleagues who were new to cancer rehabilitation.

*“I think it’s... training’s lacking really, and I have to remind myself quite a bit actually about when I get new members into my team is forgetting, I forget sometimes I think the knowledge that I have got and where it’s come from and how I can impart that onto my team and enable them to access some of that learning.” (Professional\_12 – OT)*

Therefore, this could indicate that AHPs who have not worked in the field of oncology might have difficulties accessing cancer rehabilitation specific training. Moreover, it was mentioned above that healthcare professionals interviewed had difficulties discharging people to their homes and to other hospitals due to insufficient rehabilitation services outside of the Willow and Fern Therapy Teams. Some of the interviews suggest that one reason behind insufficient rehabilitation services was that non specialist AHPs lacked knowledge and confidence to attend to people affected by cancer, and they needed education and training in oncology.

*“I think when you lack in confidence and skills in an area, it’s easier in a way, isn’t it to shy away. Yeah. So, I think there is an education need. And recently when we ran an education session for one of the Health Boards it was... yeah, it was really useful. It’s something that I think we should be doing more.” (Professional\_09 – SLT)*

*“I think there’s a lack of education. So, for some therapists, they... I think they would struggle to have a conversation with a patient who’s got a cancer diagnosis, cos they find it difficult to talk about it, particularly if you know if it’s... conversation is around end of life care and where... where does that patient sort of want to be based, so, I think some therapists find it really difficult.” (Professional\_12 – OT)*

*“the community service that are already in place, I think there’s a... I think therapists sometimes are kind of... for want to a better word... scared of kind of treating cancer*

*patients and it's probably lack of education as well on... they think 'Oh, they've got a cancer you know, we can't really do anything with them.' I think that does still exist in the community"* **(Professional\_15 – physiotherapist)**

*"The availability of different services I guess is a massive one. Maybe people's confidence in oncology. So, if they're not specific oncology services sometimes although kind of you know perceptions of cancer is continuing to change, which is fantastic, you know sometimes people do still get a little bit nervous about treating people with cancer. And helping people with cancer."* **(Professional\_16 – OT)**

In addition, this lack of knowledge and confidence can be observed in the account of Participant\_02 who got in touch with her local physiotherapy department to seek physical activity advice from healthcare professionals. Participant\_02 described that the physiotherapist seemed unsure on what to do when Participant\_02 told her that she had cancer. However, the physiotherapist sought advice and referred Participant\_02 to the Willow Therapy Team.

*"I was very concerned that my muscles wasting and that I was losing hm... strength, so I took myself down to the walk-in it's a physio unit walk-in... one in Welsh town. [...] I went and explained that I would like some basic exercises I can do in the house just to keep my muscles moving. The lady panicked as soon as I said cancer. Said 'Whoa' She seemed quite that frightened of it a bit I think and... Yeah, she w... she did react quite strongly and she shot off and got some advice. And they basically said they couldn't give me any advice at all. [...] They referred me then to the Willow nurses."* **(Participant\_02 – person affected by colorectal cancer)**

Based on the data extracts above, non-specialist healthcare professionals could benefit from education and training. Professional\_14 mentioned that training about cancer is available for non-specialist therapists and rehabilitation professionals, although later she added that a basic level cancer awareness training would be beneficial for all healthcare and even for leisure staff.

*"There's a lot of training out there."* **(Professional\_14 – OT)**

*"They [healthcare professionals and leisure staff] need to have a basic level awareness of what cancer is and there's... something that I've been musing whether it happens or it doesn't I don't know yet, but whether we could come out with something similar to the level 1 dementia awareness training, I think that would be really helpful and then everybody understands [...]"* **(Professional\_14 – OT)**

Moreover, Professional\_12 mentioned that the OTs of Fern organised a study day, where they welcomed OTs from other hospitals who were not specialised in oncology. The goal of



the study day was to help non-specialist colleagues gain confidence and new skills to work with people affected by cancer.

*“We put on an OT study day, [...] and it was building bridges... or building confidence in oncology and palliative care, [...] it was bit... thirty-five, forty people attend, it was a free event, and it was all about sort of fatigue management, anxiety management, spinal cord compression, [...] it was really well received by the OTs, because wha... it was a three days training, but actually to give them some of the confidence to sort of start thinking ‘I could do this’ and how... you know how to go about trynna sort of get some of those skills...”*  
**(Professional\_12 – OT)**

Following the information day, non-specialist therapists from other hospitals had asked to shadow Fern staff which could potentially help them gain more knowledge and confidence in their cancer rehabilitation skills.

*“I think sometimes it’s enabling people, cos after that study day I did actually have maybe two or three OTs at different times have contacted me and said ‘can I come down and do some shadowing?’ ‘come down and visit your department’ [...]”* **(Professional\_12 – OT)**

In summary, training seems to be available for healthcare professionals who specialise in oncology, although interviewees reported that their main learning came from their experience working in cancer rehabilitation. Training and education seem to be an issue for non-specialist therapists. This could affect the range and volume of cancer rehabilitation services to be provided. Not every person affected by cancer need specialist input, and not having generic services available could lead to specialists seeing people with needs that could have been dealt with by non-specialists. This could put extra strain on specialist services. As mentioned above in some extracts, big caseloads could lead to more reactive cancer rehabilitation, and the Willow and Fern Therapy Teams becoming “firefighting” services (Professional\_04) or doing “crisis management” (Professional\_12).

### 9.2.2 Professional boundaries and competency sharing

Besides the insufficient training for non-specialist therapists, there is another potential mechanism that could influence the range and volume of cancer rehabilitation services. Professional boundaries between certain groups of AHPs could serve as a mechanism that impedes cancer rehabilitation service provision through lack of competency sharing. In the Fern Therapy Team, one of the interviewees raised issues regarding professional boundaries between OTs and physiotherapists.

*“Culturally there’s a very big difference between what physios are happy for us to do perhaps and what they do down in the other Cancer Centre. It’s frowned up... it gets frowned upon.” (Professional\_12 – OT)*

These professional boundaries could result in insufficient competency sharing, disrupting continuity of care, and adding to stretched workload with potentially unnecessary contact with people affected by cancer.

*“If a physio here identifies somebody needs a second stair rail, why refer them to us when you... they’re quite capable of filling in the form to do it. It’s better the person who knows that patient best. They don’t need to come our way just for a stair rail, but culturally that’s what’s so that’s happened, you know so it’s quite big barriers in that sense...” (Professional\_12 – OT)*

Moreover, boundaries between OTs and physios in Fern manifested in the provision of exercise classes. While in Willow, OTs and physiotherapists both provided exercise classes, in Fern, it was seen as a physiotherapist responsibility.

*“There’s an old colleague of mine [...] and she was promoting the Willow activity, physical activity programme and I messaged her and I said ‘oh, are you... are you running this then?’ and she... and she said ‘yes’ she said ‘it’s OT led up here’ where is down here it’s physio led.” (Professional\_12 – OT)*

However, while Professional\_12 described professional boundaries as a mechanism that could potentially impede the provision of cancer rehabilitation services, she added that the relationship between OTs and physiotherapists were good.

*“Don’t get me wrong we [physiotherapists and OTs] do work quite well together.” (Professional\_12 – OT)*

Professional\_06, who is a physiotherapist from the Fern Therapy Team, did not mention professional boundaries between OTs and physiotherapists during the interviews, implying that physiotherapists might have not seen this as an issue. However, Professional\_12 used to work in teams where OTs and physiotherapists worked closely together prior to being employed by the Fern Therapy Team. Her experiences could have influenced how she saw the boundaries and competency sharing between Fern OTs and physiotherapists.

*“I’ve worked in some settings like when I worked in the Health Board where I’ve been very used to working closely with the physio, so for me it’s completely alien to not if you can do a joint assessment, why not do it, because it’s better for the patient, [...]” (Professional\_12 – OT)*

Besides the professional boundaries between OTs and physiotherapists, Professional\_12 mentioned that she was pushing for a change towards shared competencies between OTs and nurses in equipment prescription. She mentioned that OTs were often involved in prescribing beds to discharge people to their homes. Professional\_12 suggested that it might be better suited if the healthcare professional who had the most contact with the person prescribed beds for home. In this case, Professional\_12 argued that nurses were the most competent.

*"[...] you've got somebody that's end of life care, whose going home to be nursed in bed and they're nowhere their occupational therapy needs, it's quite intrusive as an OT to have to go in and speak to a family and then start asking questions [...] when we don't know the patient, and so therefore you're almost throwing another person into the pod at an already very distressing time. Whereas the nurses on the ward know that patient and the family inside out really. [...] they know what their pressure care needs are, so they're more than capable of actually making that referral for a bed. It went down like a lead balloon, they [nurses] didn't like it, they're still not that keen on it [...]" (Professional\_12 – OT)*

Professional\_12 added that for OTs to order beds for a person that they barely know often led to a time-consuming back and forth communication with district nurses, as the OTs were unsure about the person's pressure sore needs.

*"[...] [ordering bed] it's like it's playing telephone ping pong, so it makes more sense for a wards member of staff to be ringing that p... that you know that district nurse for example, because when they're turn around and say 'well what grade is the pressure sore?' Or 'is it blanching? Is it doing this?' I can't answer that question, whereas the nurse can." (Professional\_12 – OT)*

While Professional\_12's account indicate that professional boundaries are potential mechanisms that through the lack of competency sharing could lead to service provision issues, working across boundaries can support cancer rehabilitation. As mentioned above, the Willow Therapy Team worked interdisciplinary, across boundaries between OTs and physiotherapists. Both OTs and physiotherapists lead exercise classes or perform assessments that might typically be associated with the other profession. Professional\_16 mentioned that although she is an OT, her role could be done by either a physiotherapist or an OT.

*"So, my role is a cancer rehabilitation therapist with... within the therapy team. And my background is an occupational therapist. But the current role that I'm in could either be performed by an OT or a physio." (Professional\_16 – OT)*

Prior to the development of the Willow Therapy Team, Professional\_01 and Professional\_14 both worked in AHP teams who shared office, made shared notes, and shared competencies to ensure every person got seen.

*“In a previous team we just had joint notes. We would pool everything coming in. If someone said ‘oh this person needs to see a physio’ didn’t mean they gotta see a physio, it could have been the OT for outpatient services... did that. If as an OT I saw someone actually and said ‘Actually, no I do need a physio’ then you just pulled them in. So you do... we had the flexibility. Not all teams have that flexibility, we’re based together, it was easier.”*  
**(Professional\_01 – OT)**

*“I’ve always worked really closely with physios. I think... I think there are natural pairings within therapies, I think OT and physio work really well together, you can see how a physio and speech work really well together, you can see how speech and dietetics work really well together and there’s a lot of shared boundaries between OT and dietetics or there could be, if people were comfortable to work together.”* **(Professional\_14 – OT)**

Their experiences with sharing competencies were positive, and it showed that interdisciplinary working reduced duplication and improved communication, leading to more efficient service provision.

*“In [English location] we merged two departments, we merged an OT and a physio department. [...] Go and get the handover together, hm... they were able to prioritise their workload between themselves, many of the initial assessments we did together and then we actually started writing them up together, [...] So that, cos what we found was the wider multidisciplinary team would often say... you know home when OT happy, physio says OT needs to do X, OT says physio needs... and you would have this horrendous conversation in the medical records, so we put hm... a unified entry with a joint plan ‘OT will do X, physio will do Y’ and that’s... that’s our plan. [...] And it worked so well, it worked really really well.”*  
**(Professional\_14 – OT)**

In summary, professional boundaries can lead to insufficient competency sharing, duplication of work, and time-consuming communications between healthcare professionals. Working across boundaries seem to facilitate efficient joint assessments and competency sharing. Moreover, as seen in chapter 8, receiving care and support was more important for people affected by cancer than the professional title of the rehabilitation provider. Therefore, from the perspective of people affected by cancer, working across boundaries and sharing competencies could help provide a range and volume of services. However, to understand what influences professional boundaries, the contexts in which they act must be explored.

## 9.3 Context

In IPT\_2, it was theorised that availability of training based on the four level model (NICE 2014, Welsh Government 2010) could be a facilitating context for training needs assessment and training. In the mechanisms it was discussed that while specialist training is available and cancer specialist AHPs have the knowledge and confidence to provide cancer rehabilitation, training for non-specialist therapists might be an issue. This could indicate that the four level model does not necessarily guide and support training for professionals working as non-specialist therapists at level 1 and level 2. Moreover, the four level model requires some level of competency sharing, although as seen above professional boundaries still exist between certain AHPs and healthcare professionals. This further implies that the four level model is not a model widely followed in healthcare services. Other contexts have a greater part in influencing healthcare professionals' training and cross boundary working. First, interviewees' experiences with the four level model is presented, then contexts influencing training and professional boundaries are discussed.

### 9.3.1 Non-use of the four level model

The interviewed healthcare professionals' accounts showed that the four level model was not utilised to full extent in practice. There were healthcare professionals who were not fully aware of how the four level model could work.

*"It's... yeah, I haven't looked at it in a while. It's something like... is it the prehabilitation and... [...] I probably don't know enough about it, to give a good... a good opinion on it, really. But something that I'd... I'd look into..." (Professional\_15 – physiotherapist)*

*"I've heard about. I don't know it in great details, so no, I've just basically heard of it. [...] I think it's all very well having these levels and everything, but again it needs to come back to... you know, the appropriateness for that patient at that time, so yeah... it is something that I need to be a bit more aware of actually, cos I've... I don't know it in great detail." (Professional\_20 – OT)*

Professional\_12 seemed to have a different understanding of how the four level model could be used, indicating that specialists worked on every level. She described the four level model as a way to categorise input for people affected by cancer, based on how complex their conditions were.

*"if somebody's referred to us for fatigue management over the phone, we'll make a phone call visit... conversation with them and it might be that we can just give some of that level*

*one general advice. I tend to see level two advice fitting in as where we might stand out. The top ten tips, the Willow fatigue booklets along with our information and follow that up then with a follow-up phone call [...]. And then level three might be where we invite somebody in for a group, and then level four would be where we're doing more one to one interventions..." (Professional\_12 – OT)*

If healthcare professionals do not know how the four level model influences their practice, or have different interpretations of it, it indicates that the four level model does not have a role as a context either in supporting or inhibiting the mechanisms of training and professional boundaries. Professional\_01 mentioned that job descriptions and clinical bands had more impact on professionals' work, than the four level model. Although she acknowledged that the four level model could be used as a guidance in the training of non-specialist therapists at level 1 and 2.

*"we do whatever we need for our job descriptions and job expectations. So, we are very much focused on the work that we should be doing from an... what is our expectations of... this is the band we are, this is what we are expecting of that person in that role. From a point of view of the information and the expect... what they should be learning, I don't... we potentially do use it, but not by default. We don't consciously use it. [...] It might help us in certain ways when we're looking at service development and some of the education we do for non-cancer specialists. 'To s... this is the expectations of what we...' But if we didn't have them, I don't know that we'd do anything different." (Professional\_01 – OT)*

Professional\_13 mentioned that in Fern Therapy Team they used the four level model to some degree, but not as a formal process. For example, delegating work to the band 4 technicians.

*"We follow that in many aspects, but probably not formally hm... so there's certain sort of things like fatigue workshops that are band fours might do [...] And I think that we need to do much more looking at our tiers of input really to free up the qualified to do the much more specialist stuff, but it's not something that I would say we formalised. It's sort of an un... it's an unspoken thing that tends to happen, but I think it could be more efficient again if we have [inaudible] formalised it that much more." (Professional\_13 – SLT)*

Professional\_13's account can explain why it might be possible that certain professionals are not fully aware of the four level model. If the model is not formally followed within the cancer rehabilitation services, healthcare professionals will not be familiar with it.

Other healthcare professionals described the four level as something to strive forward, as specialist professionals will not be able to see every person affected by cancer. Professional\_14 said that the only way cancer rehabilitation could work in the long term if the four level model was more utilised.

*"I think it's the only way forward. If we're going to, you know, we currently anybody born after 1960 something has a 1 in 2 chance of having a cancer diagnosis. Now if we've got a population of 60 something million that's 30 million people that at some point are gonna have. There's no way that we gonna be able to meet the needs of all of those people... if we don't look at using our rehab professionals differently."* (Professional\_14 – OT)

In addition, Professional\_14 suggested that leisure centres and community teams should be better utilised in cancer rehabilitation.

*"we do have huge rehabilitation professional groups in the community, in secondary care, they have rehabilitation skills, they're all trained. We've got the leisure centres with... with their exercise professionals that can work with us. Not replace us, but work with us on the aspects that are their expertise. It's just working out how we get from where we are now to all of that happening that's... that's hard."* (Professional\_14 – OT)

However, Professional\_14's account shows that involving rehabilitation professionals at level 1 and 2 is challenging. Professional\_17 and Professional\_18 expressed that making sure that training is provided at lower levels based on the four level model would be the specialist professionals' duty.

*"I said it's about providing supervision and support and education to other dietitians and not even just dietitians, like I've done a lot of work in the past on training up nurses to provide first line dietary advice, so it is about yeah, providing that to the non-specialist, so you work out the Tier then... so yes, I do think it's work, but I think there needs to be a lot of work going into that"* (Professional\_17 – dietitian)

*"This is where upskilling colleagues is key. Not just... and just our CNSs [cancer nurse specialist], is just empowering them to say 'Right, you can give... nutrition is everybody's priority.' [...] Yeah, so you know as a specialist working in this role for sometime, you know we... we should retain that kind of the teaching, the education element... look developing competencies..."* (Professional\_18 – dietitian)

In addition, Professional\_17's and Professional\_18's account show that upskilling healthcare professionals based on the four level model could aid working across professional boundaries and sharing competencies. This indicates that if the four level model was in use and widely known it could be a facilitating context to training and cross boundary working. However, as seen above, some professional are not familiar with the four level model which indicates that the non-use of the four level model could be a possible inhibiting context for both training and cross boundary working.

### 9.3.2 Lack of time allocated for AHPs' training

A context negatively affecting healthcare professionals' learning and upskilling was the lack of time allocated for AHPs' training. Professional\_20 and Professional\_18 mentioned that trying to get time off can act as a barrier.

*"I think that being given study leave is getting a lot more difficult, but actually the training is out there if that's what you need and if it fits in with your your PADR, which we call it here, your... your kind of development plan then. Yeah, but I think releasing you in terms of resources is getting more difficult..." (Professional\_20 - OT)*

*"Tryna get onto study days and courses is getting increasingly difficult being released as a res... time is a resource. And people being released for that hm... that's l... I would say they're the constraints. Time, having time out to keep up with CPD, to look at your appraisal, cos t... that's the other thing..." (Professional\_18 – dietitian)*

Moreover, Professional\_12 mentioned that getting specialist training for developing new services can be difficult, due to finding time to do the training and other issues, such as cost implications.

*"And at the moment we haven't had that training. There's obviously a cost implication, there's the time factor trying to do it, and trying to source that training so, I'd say that's probably the biggest barrier to be enable to take services forward at the moment." (Professional\_12 – OT)*

### 9.3.3 Supportive management as a facilitator

The interview with Professional\_20 highlighted that although time off due to training can be an issue, a supportive management team or line manager can facilitate receiving study leave.

*"If actually it would take two days to train in a certain area then I think that our manager is... is quite hm... prudent in making sure that you can't get that knowledge without leaving the... the clinical setting for two days, which I do think is fair enough." (Professional\_20 – OT)*

Moreover, a supportive manager can facilitate supervision and reflective practice helping the provision of up-to-date cancer rehabilitation services.

*"We've instigated clinical supervision in the last six months here, so they... they haven't had any clinical supervision formally before, and we did a sort of questionnaire six months to see how they were finding it and... [...] and clinical supervision was one of the ones that came up as being a really positive change, and I think that at least allows people time to reflect on something" (Professional\_13 – SLT)*



In addition, supportive and open management, or having an all-around open-minded leadership can be a supportive context to upskill professional and break professional boundaries. Professional\_16 highlighted, that good leadership helped promote competency sharing and interdisciplinary working, particularly between cancer specialist professionals and non-specialists at the Willow Therapy Team.

*“I think probably we’ve got very good leadership, we’ve got very good managers that kind of understand the importance I guess of patients receiving rehab and that actually you know we know the tools, we’ve got the tools for our toolkit of rehab, so actually you know most people can apply it, so you don’t need to necessarily even be a... you know a... a cancer specialist to provide cancer rehab.” (Professional\_16 – OT)*

Professional\_12 also believed that the reason behind the efficient competency sharing was the leadership at the Willow Therapy Team.

*“They had a really strong force with OT, I know when there was Therapist\_30 working down there. And I think... I’m not sure whether she was sort of instrumental really in... maybe pushing the boundaries for us OTs actually, cos she’s been very proactive.” (Professional\_12 – OT)*

#### 9.3.4 Historical service organisation leading to professional boundaries

One of the reasons for the professional boundaries in the Fern Therapy Team could be traced back to the historical set up of the different professions within the team. There was a period of time when the Fern Therapy Team had no shared manager overseeing all four professional groups. The different AHPs in Fern had to fend for themselves, as they had no unifying leadership.

*“One of the things when I came into the post was that were very much silent working, and over the last you know year they’re working much more together again, all the support from each other. And even though they were in the same offices, they were still very separate. Whereas, and I think almost competing in some ways, I don’t think... it’s subconsciously, I don’t think it was a conscious thing, but I think they were thinking that they had to push forward whether be physio, OT, speech or dietetics, they had to push their cause.” (Professional\_13 – SLT)*

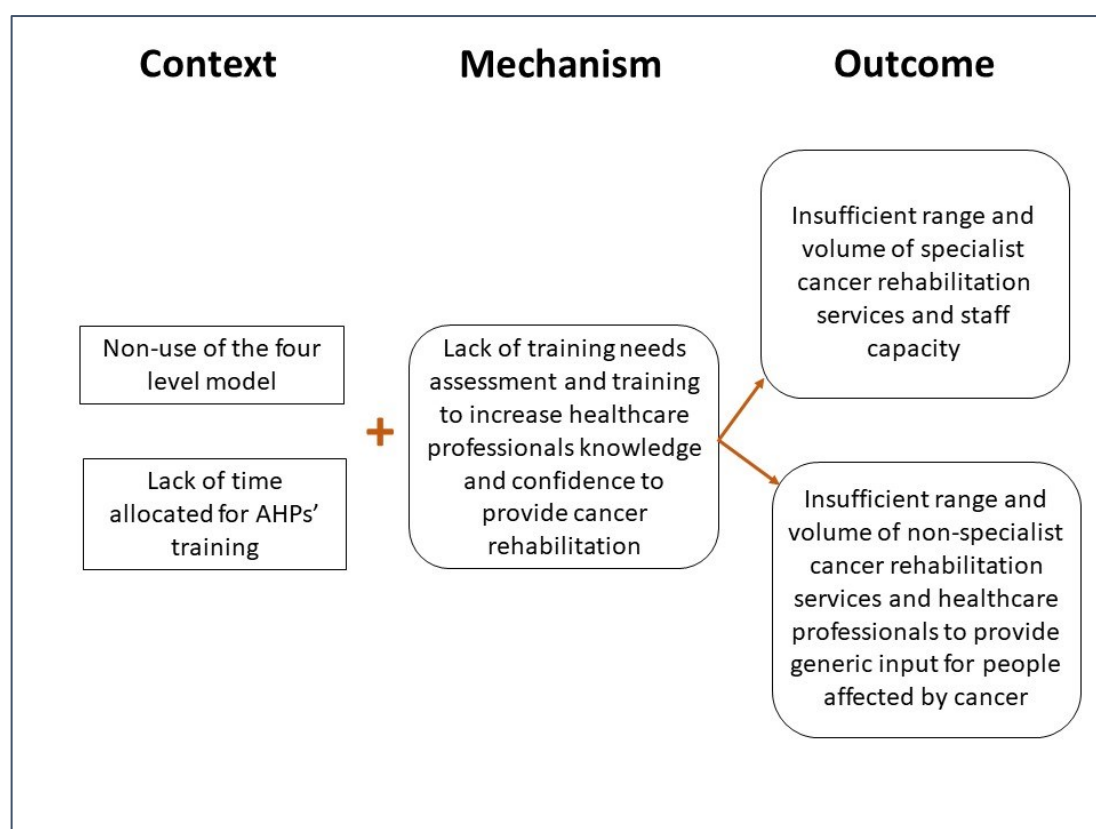
Habits and experiences developed during this period could be a potential reason why there are rigid boundaries between OTs and physiotherapists in Fern.

## 9.4 Refined CMO\_2

IPT\_2 developed prior to data collection suggested that assessing healthcare professionals training needs and providing training can increase their knowledge and confidence about cancer rehabilitation. Training would be based on the four level model, enabling the provision of a wide range and volume of cancer rehabilitation services. However, the analysis of the quantitative and qualitative data showed that cancer rehabilitation service provision was limited, mainly as issues were observed with staff capacity, limiting cancer rehabilitation provision. Moreover, issues were reported with non-specialist services which increased pressures on cancer specialist therapists, as specialist had to see people who needed generic input. This indicated that IPT\_2 did not work as initially hypothesised.

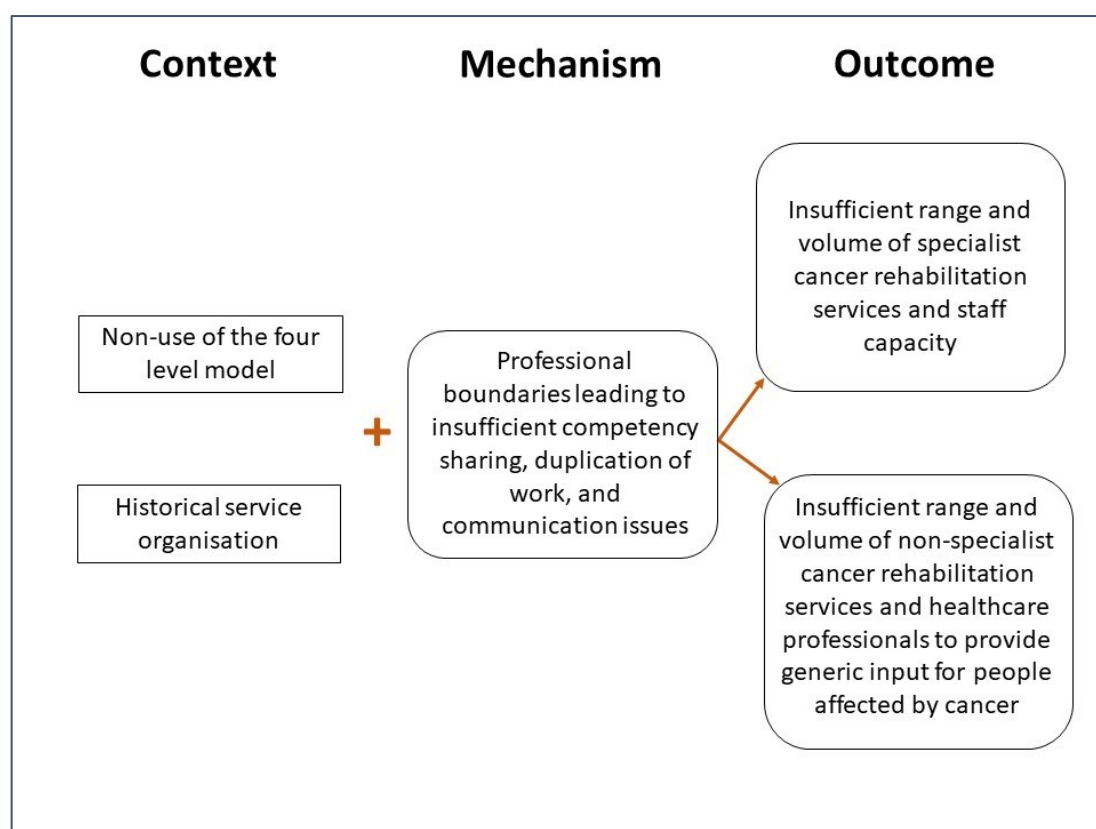
Exploring the mechanism showed that while training for specialists could be sourced, education for non-specialist therapists were often not available, leading to lack of knowledge, confidence, and skills to provide cancer rehabilitation for people affected by cancer. Potential contexts that impeded training for both specialists and non-specialists were the lack of time allocated for AHPs to attend training and the non-use of the four level model. Figure 16 shows that new refined CMO based on the data collected.

Figure 16 Refined CMO\_2



Moreover, qualitative interviews uncovered another potential mechanism that could lead to insufficient range and volume of cancer rehabilitation services. Professional boundaries existed between certain professional groups, which resulted in a lack of competency sharing, potential duplication of work, and communication issues. As a result of this mechanism there could be a lack of range and volume of cancer rehabilitation services. The contexts that inhibited cross boundary working was the non-use of the four level model, and historical service organisation that lead to different professional groups competing with each other. Figure 17 shows the alternative CMO\_2 developed based on the data collected during this PhD study.

Figure 17 Alternative CMO\_2 regarding professional boundaries



Supportive management could potentially act as a facilitating context for both training needs assessment and training provision, and for the promotion of cross boundary working. While the CMOs presented here explain some of the issues with cancer rehabilitation service provision, qualitative interviews with healthcare professionals indicated that another CMO might be behind insufficient staff capacity. This CMO is described separately as it is not a linear CMO, but rather a circular configuration.

## 9.5 The vicious cycle of time and staff capacity

Cancer rehabilitation services often start as time limited projects to explore their impact and help implementation of new services in the NHS. Some healthcare professionals in this PhD study, particularly in the Willow Therapy Team have third sector funding for a limited time. However, after the funding period ends, they might not be able to carry on providing services. This can lead to a reduction in the range and volume of services. Several professionals' accounts support that funding is an issue.

*“they’ve got the permanent funding within the Health Board, but there are other members of staff then that their funding kind of dips in and out depending on I guess you know money for projects and things like that. So yeah, then that limits what service we can provide and the sustainability of it as well” (Professional\_15 – physiotherapist)*

*“Barriers in my... post is fixed term, so as much as I’d love to stay doing this post, unless you know I seek funding or get funding from an Health Board, then I wouldn’t be able continue that post and that means that obviously then our service is at jeopardy, cos we only would have limited staff.” (Professional\_16 – OT)*

AHPs need to collect data and conduct research to provide evidence that the rehabilitation services work. Data can help gain funding for service development, employment of new staff, and extending time limited roles.

*“I’m also collecting a lot of data to try and prove my post in three... two and a half years time.” (Professional\_17 – dietitian)*

Moreover, data can help promote cancer rehabilitation services.

*“So, I think we do need to imbed ourselves in research more in things like audit more. I think we need kind of patient data off our fingertips. We almost need kind of promotion base hm... in order to be able to... to progress.” (Professional\_09 – SLT)*

However, AHPs often do not have the time to collect data or do other service development activities.

*“I think more time to be able to prom... promote our services.” (Professional\_09 – SLT)*

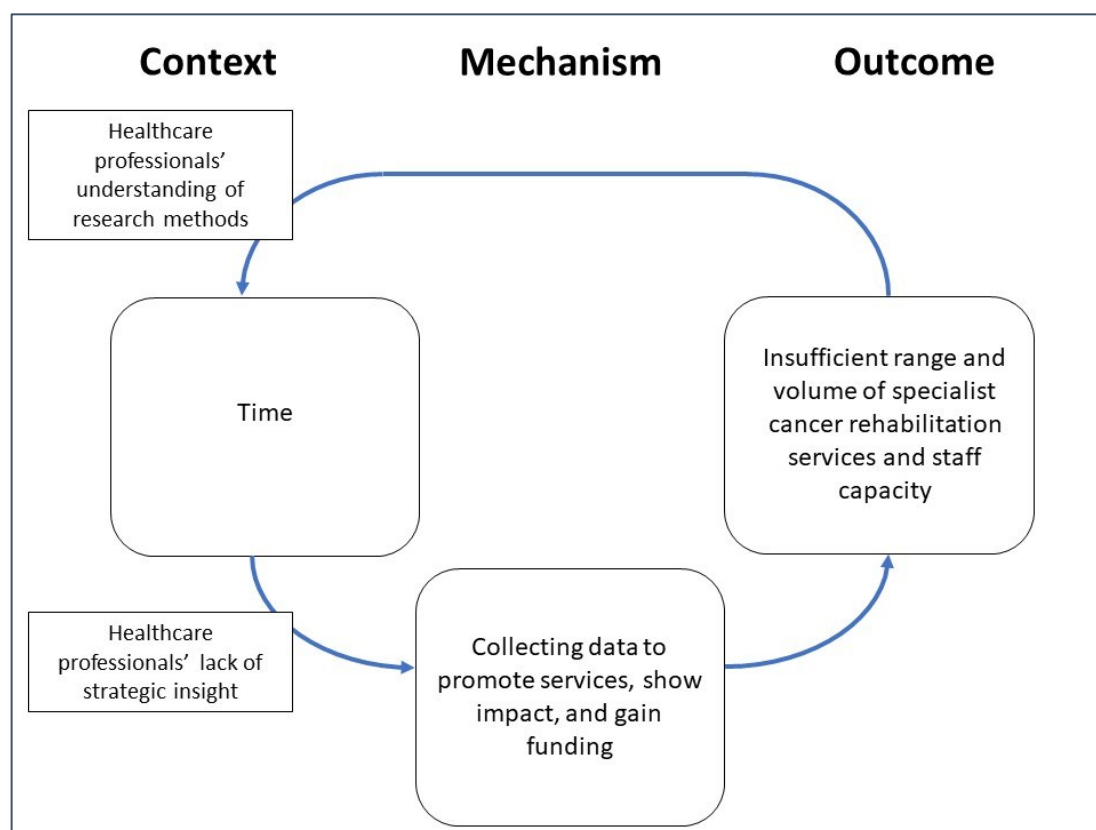
*“I would love to be able to provide more support to my patients inbetween clinic appointments for example, but that’s creeping into then my service development and admin time, and I’m aware that although patients come first, sometimes service development is needed to improve long-term patient care, so you’ve got to like balance that up and that’s quite difficult sometimes.” (Professional\_17 – dietitian)*

*“There’s not enough time for... I think doctors the only profession where they have work plans that factor in admin time and teaching time whereas with nursing and AHPs it doesn’t get, seem to get factored into our job plans, so I’m very keen you know, if I can influence our team leads to try and make sure there is dedicated time, to take time out to pause and reflect and to think and to do service improvement.” (Professional\_18 – dietitian)*

These issues with time are also represented in the fact that even though the Willow Therapy Team collected data, they did not have time to analyse it. Therefore, the secondary analysis of that routine data was conducted in this thesis. Healthcare professionals’ lack of time often stem from insufficient staff capacity. This is a vicious cycle as without data, cancer rehabilitation services have no funding, leading to no new staff and no time to

collect data. This is a process that cannot be described by a linear CMO configuration, but as a circular model. Staff issues will always lead to lack of time and prioritising the provision of already existing services over collecting data for funding applications. Pictorial depiction of this vicious cycle is presented in Figure 18.

Figure 18 The vicious cycle of time and staff capacity



In this circular model range and volume of services and staff capacity are the outcomes. However, this outcome can affect the context, which is time. Having a circular model is not alien from realist evaluation, as its ontological depth entails the concept of emergence in which the outcome of a mechanism can influence the context. However, here this does not necessarily result in a new causal explanation, but in a never-ending cycle of being short of staff.

Moreover, data collection and research can be influenced by two other contexts. Professional\_13 mentioned that some AHPs lacked the strategic insight into why collecting data was necessary. Healthcare professionals saw data collection as an added paperwork, and often did not see the broad picture that without data, funding for the services could be cut or would not be awarded for new services.

*“I think there’s always a bit of reluctance, isn’t it? To add extra what they feel is paperwork to, what they already have. I think it’s probably ag... again maybe not all of them having a strategic role to understand the importance of it, [...] I’d hate them to be in a position where they go for funding for a new service and because they don’t have the data they don’t get it. [...] it’s not always appreciating the strategic influence of that sort of... type of data. But also the improvement inpatient care that will result from it, because if we’re not measuring... I know, if we’re not measuring outcome, how do you know what we’re doing is effective?” (Professional\_13 – SLT)*

The fact that the Fern Therapy Team only started collecting data since Professional\_13 joined them indicates that these issues with strategic insight were present in the team.

The other context is the healthcare professionals’ understanding of research methods when collecting the data. If healthcare professionals’ do not have a shared knowledge and understanding of research methods, this could affect the ways they collect the data and its quality. In this PhD study, some issues with how the routine data was collected could be detected throughout the secondary analysis. In chapter 7, it was mentioned that variations existed in the sample size of the different outcome measures. This variation was the result of healthcare professionals leaving outcome measures out if the person did not have issues within the given domain. From an analytical point of view this was an issue, as it often made it difficult to differentiate between people who did not have a problem in the given health domain and people who disengaged from the service and did not return for their post rehabilitation assessment. Therefore, all missing data had to be removed from the analysis.

Healthcare professionals collecting the data need to make sure everyone in the team knows that missing data due to disengagement from cancer rehabilitation have to be coded differently from people whose outcome measure responses were not recorded due to professional judgement. Moreover, episode 0 only being reported until 2016 indicates that different professionals reported data differently. When a healthcare professional left in 2016, no episode 0 was reported any longer, indicating that reporting episode 0 was a personal habit. This could indicate that there was no consensus between healthcare professionals on how data was coded. These issues if data is not managed adequately, could influence the analysis and the quality of the evidence. If there are issues with the quality of the evidence, this could have an impact on funding and financial support of services, and through that indirectly affect the range and volume of cancer rehabilitation services.

## 9.6 Conclusion

This chapter introduced the data analysis findings related to IPT\_2. The findings show that providing a wide range and volume of cancer rehabilitation services was not always possible, due to issues with training and professional boundaries. Moreover, the importance of data collection and research was highlighted, as having sufficient data can promote cancer rehabilitation and help gain funding for new staff and services. However, professionals lack of time can be an inhibiting context resulting in a vicious cycle of staff and time issues. The next chapter presents the findings related to IPT\_3 and IPT\_4.



## Chapter 10: Individualised, tailored cancer rehabilitation

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In this chapter the findings of the realist evaluation are presented regarding IPT\_3 and IPT\_4, previously introduced in chapter 4. Although, these IPTs were considered to be separate at the outset of this PhD study, throughout the analytic process it was found that the outcomes, the mechanism, and the contexts were similar. Therefore, IPT\_3 and IPT\_4 are discussed together. In this chapter, first the outcomes are presented, then the mechanisms and contexts. Finally, the new refined CMOs are introduced. IPT\_3 and IPT\_4 aimed to investigate if individualised care could reduce health needs and rehabilitation interventions could improve quality of life. The two IPTs are shown below, for ease:

**IPT\_3:** Dynamic, individualised, tailored cancer rehabilitation (**mechanism**) can lead to reduction in people's healthcare needs (**outcome**) if care is based on routinely conducted health needs assessment (**context**).

**IPT\_4:** Accessible cancer rehabilitation, run by a trained multidisciplinary team with the capacity to see people in the region (**context**) can lead to enhanced quality of life and functional outcomes (**outcome**). In addition, cancer rehabilitation can help people with "getting back to normal" or with adapting to reduced capacities and fatigue (**outcome**). These outcomes could be achieved by building up and maintaining people's physical capacity and strength with physical exercise (**mechanism**) and improving self-management through psychosocial and educational interventions (**mechanism**).

### 10.1 Outcomes – Rehabilitation needs and quality of life

IPT\_3 and IPT\_4 hypothesised that individualised, tailored care, physical exercise, and psychosocial interventions can improve people's quality of life and reduce their health needs. In this section first the findings of the secondary analysis are introduced, presenting change in outcome measures post rehabilitation to determine if quality of life and functional outcomes improved. Then, based on the qualitative interviews the met and unmet needs of people affected by cancer are presented to see if cancer rehabilitation reduced people's health needs.

### 10.1.1 Changes in quality of life and other outcome measure data post cancer rehabilitation

The database of the Willow Therapy Team has been introduced in chapter 7, including sample sizes available for analysis. Here, the results of the pre and post rehabilitation outcome measure data analysis is presented. As mentioned in chapter 5, five outcome measures were available for comparison: FACIT-F, TUAG, QOL, pain and SOB scales. Outcome measure data were collected pre and post a 12-week rehabilitation episode. Up to 12 episodes were reported in the database, indicating that there were participants who started or attended 12 rehabilitation programmes, each lasting 12-weeks. Moreover, data was analysed in each year separately.

In 2014, the highest number of episodes reported were 10. People who had 10 episodes by 2014 had their first episode prior to the service starting to collect data. Not many participants had more than two episodes, thus the sample size of the different episodes reduced gradually with increasing episode numbers. This resulted in late episodes having too low sample size for meaningful statistical comparison. Moreover, as seen in chapter 7, sample sizes for the different outcome measures varied, as healthcare professionals often collected data based on their judgement. For SOB in 2014, sample sizes were too small for data analysis for every episode. For the rest of the outcome measures, sufficient sample sizes were available up to episode 5. Sample sizes are presented in Table 18, chapter 7.

Before pre and post rehabilitation data were compared, distributions were determined first. In 2014, the following outcome measures and episodes were normally distributed: episodes 1 and 2 for FACIT-F; episodes 2, 3, 4 and 5 for QOL. In these episodes paired t-test was used to compare data pre and post rehabilitation. All TUAG and pain data deviated from normal in every episode; therefore, Wilcoxon signed-rank test was used to analyse pre and post rehabilitation data for these outcome measures. Statistically significant improvement ( $p < 0.05$ ) was found for **FACIT-F** ( $t(54) = -4.069$ ,  $p = 0.000$ ,  $r = 0.484$ ), **TUAG** ( $T = 665.500$ ,  $p = 0.000$ ,  $r = 0.493$ ), **QOL** ( $T = 2560.500$ ,  $p = 0.000$ ,  $r = 0.550$ ), and **pain** ( $T = 30.000$ ,  $p = 0.000$ ,  $r = 0.676$ ) in episode 1. In episode 2, **FACIT-F** ( $t(25) = -3.300$ ,  $p = 0.003$ ,  $r = 0.551$ ), **TUAG** ( $T = 161.000$ ,  $p = 0.000$ ,  $r = 0.546$ ), and **QOL** ( $t(39) = -3.169$ ,  $p = 0.003$ ,  $r = 0.453$ ) had a statistically significant improvement compared to pre rehabilitation data. Mean and median outcome measure scores changes are presented in Appendix 25. These findings indicate that

people's quality of life, fatigue, functional mobility, and pain improved after their first and second 12-week rehabilitation programme.

Table 22 Effect sizes (r) calculated for pre and post rehabilitation episode t-tests and Wilcoxon signed-rank tests in 2014

Episode number	Pre and post rehabilitation effect size (r) in 2014				
	FACIT-F	TUAG	QOL	PAIN	SOB
1	0.484***	-0.493***	0.550***	-0.676***	Low
2	0.551**	-0.546***	0.453**	-0.346	NVC
3	0.376	-0.297	0.345	Low	NVC
4	Low	-0.287	0.060	Low	Low
5	Low	0.168	0.061	Low	NVC
<b>Key:</b> NVC – No valid cases; Low - low sample size (n<10); Episodes where significant difference was detected: *p<0.05, **p<0.01, ***p<0.001; Cohen (1988): 0.1<r small; 0.3<r medium; 0.5<r large					

No statistically significant difference was found in any other episodes. Table 22 shows the effect sizes for up to episode 5. Based on Cohen's (1988) effect size classification, significant cases had medium to large effect, indicating that the post rehabilitation episode improvements were substantial. Moreover, medium effect size was detected for FACIT-F in episode 3, QOL in episode 3, and pain in episode 2. This could indicate improvement in fatigue, quality of life, and pain, although as no statistical significance was detected it is possible that these findings were by chance.

In 2015, the following outcome measures and episodes had normal distribution: episodes 1 and 3 for FACIT-F; episodes 1 to 3 for QOL; episodes 2 and 3 for pain; episodes 1 for SOB. In these episodes paired t-test was used to investigate change between pre and post rehabilitation data. The rest of the episodes in 2015 and TUAG in every episode were non-normally distributed. Therefore, Wilcoxon signed-rank test was used to analyse the data. Statistically significant improvement ( $p<0.05$ ) was found for **FACIT-F** ( $t(100)=-3.863$ ,  $p=0.000$ ,  $r=0.360$ ), **TUAG** ( $T=1202.5$ ,  $p=0.000$ ,  $r=-0.521$ ), **QOL** ( $t(125)=-3.818$ ,  $p=0.000$ ,  $r=0.323$ ) and **pain** ( $T=461$ ,  $p=0.000$ ,  $r=-0.445$ ) in episode 1. In addition, statistically significant positive change was detected for TUAG in episode 2 ( $T=282.5$ ,  $p=0.008$ ,  $r=-0.391$ ), and episode 3 ( $T=116$ ,  $p=0.048$ ,  $r=-0.368$ ). Mean and median scores pre and post rehabilitation are presented in Appendix 26. Effect sizes presented in Table 23 show a substantial change between pre and post rehabilitation episodes, as medium and large effect sizes were detected in statistically significant outcome measure differences. These changes indicate that people's fatigue, quality of life, functional mobility, and pain

improved following their 12-week rehabilitation episode. Moreover, functional mobility kept improving with increasing episode numbers.

Table 23 Effect sizes (r) calculated for pre and post rehabilitation episode t-tests and Wilcoxon signed-rank tests in 2015

Episode number	Pre and post rehabilitation effect size (r) in 2015				
	FACIT-F	TUAG	QOL	PAIN	SOB
1	0.360***	-0.521***	0.323***	-0.445***	0.213
2	-0.03	-0.391**	0.032	0.213	-0.489
3	0.022	-0.368*	0.169	0.220	Low
<b>Key:</b> Episodes where significant difference was detected: *p<0.05, **p<0.01, ***p<0.001; Cohen (1988): 0.1<r small; 0.3<r medium; 0.5<r large					

No statistically significant change was detected in any other episodes. However, medium effect size was detected for SOB in episode 2, indicating a reduction in participants' breathlessness. As this episode was not statistically significant for SOB, the improvements in breathlessness could have happened by chance. Meaningful statistical analysis was possible for up to episode 3 due to the sample sizes. Sample sizes are presented in Table 19 chapter 7.

Table 24 Effect sizes (r) calculated for pre and post rehabilitation episode t-tests and Wilcoxon signed-rank tests in 2016

Episode number	Pre and post rehabilitation effect size (r) in 2016				
	FACIT-F	TUAG	QOL	PAIN	SOB
1	0.504***	-0.354*	0.341**	-0.332**	0.033
2	-0.134	-0.381	0.233	0.017	-0.218
3	0.258	-0.346	0.064	-0.361	0.616*
<b>Key:</b> Episodes where significant difference was detected: *p<0.05, **p<0.01, ***p<0.001; Cohen (1988): 0.1<r small; 0.3<r medium; 0.5<r large					

In 2016, data distribution was normal in the following outcome measures and episodes: episode 1 for FACIT-F; episode 2 for QOL and pain. In these episodes, the parametric paired t-test was used to compare pre and post rehabilitation scores. For TUAG and SOB, data distribution deviated from normal in every episode. To analyse the non-normally distributed data, Wilcoxon signed-rank test was used. Statistically significant improvements were observed in episode 1 for **FACIT-F** (t(74)=-5.016, p=0.000, r=0.504), **TUAG** (T=747, p=0.002, r=-0.354), **QOL** (T=1548.5, p=0.002, r=0.341), and **pain** (T=611, p=0.004, r=-0.332).

These changes were substantial, as the effect sizes ranged between medium and large. Effect sizes in 2016 are presented in Table 24. These findings indicate that fatigue, functional mobility, quality of life, and pain improved after the first 12-week rehabilitation.

However, not every statistically significant episode indicated improvement. In episode 3, SOB significantly increased post rehabilitation ( $T=49$ ,  $p=0.026$ ,  $r=0.616$ ), indicating deteriorating breathlessness. Due to the nature of cancer, people's health can deteriorate, or recurrence could happen resulting in worsening breathlessness. Other outcome measures do not support overall health deterioration in episode 3, although these results were not statistically significant. Some of the outcome measures, such as TUAG and pain showed an improvement equivalent to a medium effect size, although as these results are not statistically significant, these changes could be by chance. Mean and median pre and post rehabilitation data is presented in Appendix 27.

Table 25 Effect sizes ( $r$ ) calculated for pre and post rehabilitation episode t-tests and Wilcoxon signed-rank tests in 2017

Episode number	Pre and post rehabilitation effect size ( $r$ ) in 2017				
	FACIT-F	TUAG	QOL	PAIN	SOB
1	0.257	-0.582***	0.282*	-0.295*	-0.210
2	0.074	-0.506*	-0.058	-0.042	0.117
3	0.083	-0.612*	0.232	0.063	Low
<b>Key:</b> NVC – No valid cases; Low - low sample size ( $n<10$ ); Episodes where significant difference was detected: * $p<0.05$ , ** $p<0.01$ , *** $p<0.001$ ; Cohen (1988): $0.1<r$ small; $0.3<r$ medium; $0.5<r$ large					

In 2017, data was normally distributed in the following outcome measures: episodes 1 and 3 for FACIT-F; episode 2 for SOB. In these episodes and outcome measures the parametric paired t-test was used to compare pre and post rehabilitation data. In TUAG, QOL and pain data distribution deviated from normal in every episode. In these outcome measures and the rest of the episodes in FACIT-F and SOB, the non-parametric Wilcoxon signed-rank test was used for analysis. Statistically significant improvement was detected in episode 1 for **TUAG** ( $T=116.5$ ,  $p=0.000$ ,  $r=-0.582$ ), **QOL** ( $T=834.5$ ,  $p=0.026$ ,  $r=0.282$ ) and **pain** ( $T=275.5$ ,  $p=0.027$ ,  $r=-0.295$ ). Moreover, TUAG had statistically significant pre and post rehabilitation differences in episode 2 ( $T=61.5$ ,  $p=0.011$ ,  $r=-0.506$ ) and episode 3 ( $T=16.0$ ,  $p=0.022$ ,  $r=-0.612$ ). TUAG changes had a large effect size, indicating substantial improvement in functional mobility through three episodes. However, QOL and pain scale changes in

episode 1 only had a small effect size, indicating minor improvement in quality of life and people's pain. Mean and median pre and post rehabilitation data are presented in Appendix 28. No statistically significant changes were detected for any other outcome measures and episodes. Sample sizes were small for these episodes, indicating minor changes.

In summary, statistically significant improvements were detected in most outcome measures throughout the years, apart from SOB. This could indicate that cancer rehabilitation might have a positive impact on functional outcomes and quality of life, but not on breathlessness. Positive improvements were mainly detected in the first few episodes, although sample size gradually decreased with increasing episode numbers; therefore, results in later episodes might not be generalisable. Moreover, not having statistically significant difference does not necessarily mean that cancer rehabilitation did not have an impact. As health deterioration could occur with a cancer diagnosis, maintenance can be a goal of cancer rehabilitation. However, this hypothesis could not be fully tested due to not having matched control groups. Moreover, sample sizes after episode 3 were usually too low for statistical analysis; therefore, it could not be determined if any generalisable major health changes occurred with longer, continuous attendance in cancer rehabilitation programmes. The next section explores people's experience with cancer rehabilitation, and how the Willow and Fern Therapy Team helped to meet people's health needs.

#### 10.1.2 Met needs of people affected by cancer post cancer rehabilitation based on qualitative interviews

As seen above, positive functional and quality of life changes can be observed after exercise-based cancer rehabilitation. In addition, qualitative interview findings support that cancer rehabilitation had a positive impact on people's health needs. In this section first, the met physical health needs of people affected by cancer are presented.

##### *10.1.2.1 Meeting physical health needs*

People affected by cancer who attended either the exercise classes run by the Willow Therapy Team, or the services of the Fern Therapy Team reported improvements in their physical health. As seen above, TUAG times often reduced post rehabilitation by the Willow Therapy Team, indicating improved functional mobility. Moreover, reduced pain was

detected. These changes are supported by the interviews conducted with people who attended the exercise classes run by the Willow Therapy Team. Many people affected by cancer reported improved mobility and physical fitness post rehabilitation.

*“Since I’ve been having the hydrotherapy, I’ve been able to walk a lot farther. When I started the hydrotherapy, I couldn’t walk 50 yards without a stick. Now I could probably do half a mile, maybe even a mile.” (Participant\_10 – person affected by prostate cancer)*

*“Feel a lot better, a lot fitter, I certainly don’t feel dizzy when I come out, which many of time I felt walking from the car park [...]” (Participant\_16 – person affected by prostate cancer)*

Other people affected by cancer reported that although they noticed positive changes in their mobility and strength following their rehabilitation episodes run by the Willow Therapy Team, they were still not fully back to how they were before their diagnosis.

*“It definitely helped, definitely helped to make me feel like I was... I mean I still have difficulty sometimes getting out of the chair now, but again so many people that are worse than me, and I’ve seen other people there improve so much, unbelievable.” (Participant\_02 – person affected by colorectal cancer)*

*“My arm still hasn’t come strong enough to pick up a full cup of coffee. I leave it cool a lot and then I have to have two hands to drink my coffee. To pick up a kettle is pretty good, shakes an awful lot, or a full jug of water. But I’m working on it. I’m getting there.” (Participant\_28 – person affected by breast cancer)*

Some of the participants whose physical health improved but not as much as they would have liked acknowledged that it might not be possible to return to “normal” due to the permanent impact of cancer.

*“I’m still not there where I would like to be, because I’m nothing like I used to be before I found out I had prostate cancer, I... and I know that I probably will never get back to that level, but I feel it’s definitely been a good thing to do and I’m glad that I referred myself to Willow [...]” (Participant\_09 – person affected by prostate cancer)*

Other participants mentioned that although their mobility improved, their other comorbidities were an issue that impeded full recovery.

*“I feel that I tackle the stairs at home a little bit better and then some days I get up and you... you know I just don’t want to get out of bed, you know? And everything’s... everything is painful, but I suppose that’s... I don’t know, the effects of arthritis, but that’s arthritis rather than anything else, [...]” (Participant\_30 – person affected by prostate cancer)*

While some of these physical mobility issues cannot be fully restored by the exercise classes provided by the Willow Therapy Team, cancer rehabilitation enabled people to manage

their condition by returning to physical activities they did prior to their cancer diagnosis or start new exercise regimes outside of the Willow Therapy Team classes.

*"I'm moving a lot better than I was. Yeah, definitely. It's been really good. And it's got me to the stage now where I'm gonna go back in swimming and I get my life back, I'm getting my life back."* **(Participant\_02 – person affected by colorectal cancer)**

*"So, I got my last appointment then on Friday. 2.30 with... Therapist\_01, and I started up in the leisure centre."* **(Participant\_16 - person affected by prostate cancer)**

*"I'm more or less finished my time with them [Willow] now, that I can move on. So, I've already taken up [Pine Centre]'s time in the beginning and I followed the Tai Chi instructor to [leisure centre], where I pay for my Tai Chi lessons now."* **(Participant\_28 – person affected by breast cancer)**

People engaging in exercises outside of the Willow Therapy Team to manage their own mobility issues indicates that self-management can be the outcome of rehabilitation. Originally it was theorised in IPT\_4 that self-management was part of the mechanism in which cancer rehabilitation interventions helped to improve quality of life. However, as cancer and its treatments resulted in permanent health changes and some people had comorbidities that impacted on their physical health, the goal of cancer rehabilitation was often to teach skills that could help people manage their conditions at home.

*"So, if they said that actually they were fatigued we would put them into an intervention that was gonna help with their fatigue or we give them skills that they could also be using at home."* **(Professional\_01 – OT)**

While people affected by cancer interviewed from the Fern Therapy Team did not participate in exercise classes, some of them received acupuncture or were given information on swallowing that had positive impact on their physical health. Participant\_18 and Participant\_21 received acupuncture for their hot flushes which reportedly reduced after six sessions.

*"It's from week one of having it, I noticed a reduction in the hot flushes, and then after 2 weeks I started to sleep through the night again, so it made a really huge difference."* **(Participant\_21 – person affected by breast cancer)**

*"I've gone with the acupuncture and it has improved things [hot flushes] slightly. It hasn't gone completely, but it's improved things, [...]"* **(Participant\_18 – person affected by breast cancer)**



Participant\_27 had swallowing difficulties, particularly while eating. While he did not consider the swallowing issues a major problem, he appreciated the information received from the SLT and the dietitian on changing his eating habits.

*“I am more aware about eating a bit slower and drinking, even drinking a bit slower [...] I’m more aware to... to chew longer and... and take my time with my food, which helps a lot.”*  
**(Participant\_27 – person affected by lung cancer)**

The above extracts show that cancer rehabilitation interventions, such as exercise classes and acupuncture have a positive impact on physical issues, meeting people’s health needs. In addition, these cancer rehabilitation interventions did not only improve physical health but helped meeting people’s psychological health needs.

#### **10.1.2.2 Positive impact on psychological health and sleeping**

Some of the interviewees who attended the exercise classes run by the Willow Therapy Team mentioned that they also had psychological health needs. Many of these participants did not expect that the exercise classes could have a positive impact on their mental health. However, they welcomed the improved changes in their mental health, and praised the Willow Therapy Team for meeting these needs.

*“I’m now able to wind myself down a little bit when I get wound up. At the things that I stress about, I used to find that I used to overreact to horrible people, very badly and I used to get really upset. [...] I’m not as anxious and stressed out about it and I’m able to calm myself down more.”*  
**(Participant\_02 – person affected by colorectal cancer)**

*“Without it... [exercise classes] I think I would be a lot more depressed and a lot more within myself [...]”*  
**(Participant\_09 – person affected by prostate cancer)**

*“It’s [hydrotherapy] made... slightly more mobile. And it’s [hydrotherapy] done me good. But I mean, psychologically it’s done wonders.”*  
**(Participant\_10 – person affected by prostate cancer)**

In addition, Participant\_37 reported that attending the fatigue management group run by the Fern Therapy Team helped her accept that cancer altered her life, and she might not ever return to the person she used to be before her diagnosis.

*“I think it’s [fatigue management group] forced me to admit that I’m not who I was, and I can’t go back. Cos I keep thinking ‘Oh, but I used to be able to do this, why can’t I do this?’ And now it’s about thinking ‘OK, give yourself a break, you have had cancer. You need to calm down. You need to slow down.’[...]”*  
**(Participant\_37 – person affected by breast cancer)**

Moreover, some participants reported improved sleep after the different rehabilitation interventions. As seen above, Participant\_21 reported improved sleep after acupuncture, which was the result of reduced hot flushes. Participant\_02 and Participant\_03 experienced improved sleep due to reduced stress and their improved ability to relax.

*“And obviously severe illness, you’re tired, you’re gonna sleep well anyway and a lot more than normal, but I find now, that if I go to bed and I’m able to relax myself down and get to sleep more easily.”* **(Participant\_02 – person affected by colorectal cancer)**

*“I couldn’t go to sleep some nights, you know I just couldn’t relax. But now I can.”* **(Participant\_03 – person affected by breast cancer)**

In summary, the different cancer rehabilitation interventions helped improve physical and mental health, while meeting people’s needs. Other people started to engage in self-management, such as attending their local leisure centres nearing the end of their cancer rehabilitation interventions. In addition, improved sleeping and help with acceptance of changed physical capacity post treatments were described by a few people affected by cancer. However, some people affected by cancer indicated that they had certain unmet health needs.

### 10.1.3 Unmet health needs of people affected by cancer

While the interviewees were generally satisfied with the rehabilitation interventions that they received from the Willow and Fern Therapy Teams, some people still had health needs and cancer treatment related side effects that they would have liked to receive support with. People affected by prostate cancer attending the Willow Therapy Team expressed that hot flushes were an issue. Participant\_01 and Participant\_12 both suffered from hot flushes which had debilitating consequences impacting on their daily activities.

*“I usually get two in the night though. And they are very intense and I only... my feet get REALLY HOT and VERY PAINFUL, like they are being burnt.”* **(Participant\_01 – person affected by prostate cancer)**

*“But on a bad day, when it’s hot, I get them [hot flushes] away, but they keep coming back, one after the other, and that does affect me when I’m driving people to hospital. I don’t like to stop say ‘I’m sorry, I can’t drive.’ I’ve got to get them here. I don’t like sitting in the layby for an hour, read, drink lots of water.”* **(Participant\_12 – person affected by prostate cancer)**

Both participants managed these cancer treatment related side effects in different ways. Participant\_01 was seeing a naturopath privately, while Participant\_12 decided to try private acupuncture.

*"I just went to see [Naturopath\_01], because I said 'I'm just worn out from these hormones and hot flushes.' And she said 'well I can't resolve that [inaudible], but I can give you a better diet.'"* **(Participant\_01 – person affected by prostate cancer)**

*"I'm going on Tuesday to have some acupuncture, and I've been told that will help..."* **(Participant\_12 – person affected by prostate cancer)**

These recollections could indicate that people affected by cancer need to attend several services to have specific health needs met and ease their cancer treatment related side effects. Moreover, these services result in out of pocket expenses for people affected by cancer. However, Professional\_19 mentioned that she provided acupuncture for outpatients within the Willow Therapy Team.

*"I do see outpatients mainly for acupuncture"* **(Professional\_19 – physiotherapist)**

Therefore, it was unclear why people affected by cancer had to seek acupuncture somewhere else. Potential contexts that could explain why Participant\_01 and Participant\_12 did not receive acupuncture at the Willow Therapy Team are presented in the next section.

In addition to hot flushes, Participant\_09 expressed that general pains and aches were a common cancer treatment related side effect, and he believed the Willow Therapy Team should offer complimentary therapies to manage these.

*"Acupuncture or a massage type... service of... again could be part of the rehab, could be another possibility then. Because obviously when you're exercising you're aching and things like that or... sometimes you don't feel like exercising because the body's aching too much. And some people maybe... the ones who perhaps don't feel they could exercise, but they could have a benefit from some of the complimentary therapies."* **(Participant\_09 – person affected by prostate cancer)**

Regarding the exercise classes provided by the Willow Therapy Team, Participant\_30 mentioned that he felt people affected by cancer would benefit from a more intensive cancer rehabilitation regime. He suggested that the sessions should be more frequent than once a week.

*“Once a week is not enough. I know that there’s a big strain on people, it would be nice that maybe initially be... maybe have two or three sessions.”* **(Participant\_30 – person affected by prostate cancer)**

Interviewees who attended the Willow Therapy Team did not mention other health needs that cancer rehabilitation services could have helped with. People affected by cancer who attended services run by the Fern Therapy Team mentioned a few health needs that they had after receiving input from Fern healthcare professionals. Participant\_29 expressed unmet psychological health needs, and he hoped that as part of the fatigue management group he would receive more psychological support, or at least more specific information on different psychotherapies that he could access. The fatigue management group offers four sessions within four weeks, with each session focusing on a topic, such as diet, relaxation, psychological input, and pacing activities. One out of the four sessions is run by the psychology team of the hospital where the Fern Therapy Team is located. However, Participant\_29 expressed that this psychological support was not sufficient, and the information was generic.

*“The psychological input into the fatigue management was just very broad. You know, and it didn’t kind of target empowering people with tools to help. That’s... yeah. So that didn’t quite meet the needs.”* **(Participant\_29 – person affected by prostate cancer)**

In support of that, Participant\_37 mentioned that the information received at the fatigue management group was quite general.

*“In terms of the course content it’s not really rocket science, it was stuff that I pretty much heard before, you know, about healthy eating, making sure that you’re managing your energy levels and stuff...”* **(Participant\_37 – person affected by breast cancer)**

However, as mentioned above, Participant\_37 praised that the fatigue management group for helping her accept her changed health condition. Moreover, she mentioned she was not sure what else could be said during these groups.

*“In terms of the content I don’t know what else you can say really, cos like I said it’s not rocket science, it’s about looking after yourself and managing your expectations.”* **(Participant\_37 – person affected by breast cancer)**

In addition, it must be mentioned that both Participant\_29 and Participant\_37 were quite proactive people regarding help seeking and managing their health condition. Therefore, information received at the fatigue management groups might have been generic for them but might have been sufficient for other people with less knowledge on fatigue and cancer

treatment related side effects. Regardless, this could indicate that the Fern Therapy Team needs to tailor the fatigue management groups for people who have more specific psychological and information needs.

Besides the reported insufficient psychological input in the fatigue management group, other people who received cancer rehabilitation interventions from the Fern Therapy Team reported some unmet health needs. Participant\_18 had joint pains all over her body as a side effect of her cancer treatments. Prior to her cancer diagnosis she received hormone replacement therapy (HRT) for years which she had to stop taking when she was diagnosed with breast cancer. That is when her joint pains started which stopped her doing her usual activities and forced her to make major changes to her lifestyle, such as stopping playing golf. Her oncology MDT assumed her joint pains were the side effects of the Tamoxifen and the HRT withdrawal; therefore, Tamoxifen treatment was stopped. However, this did little to ease her pain. For her joint pains she was offered pilates by the Fern Therapy Team. However, after her initial assessment, the physiotherapist recommended that she did not attend pilates, as Participant\_18 had issues with lying down and getting up from the floor.

*“But they did suggest in Fern did I want to have pilates as a therapy and I saw the physio to do with that, but because of my inability to get up and off the floor, she said, you know it w... I wouldn’t be a suitable patient for that, so... That I haven’t... I’m not having that. So, yeah. No, I haven’t got any help regarding my joints at all.”* **(Participant\_18 – person affected by breast cancer)**

While it was established that Participant\_18 was not suitable for pilates, no alternative input was offered for her by the Fern Therapy Team. This could indicate that the Fern Therapy Team might not be able to tailor some of the interventions they offer. However, it must be considered that Participant\_18 contacted me 3 months post interview and she said she went back on HRT, which reduced her joint pains. Therefore, it might have not been possible to manage her joint pains solely with physiotherapy input.

Moreover, Participant\_21 expressed that she had some issues with fatigue and joint pains. However, she was not offered pilates or referral to the fatigue management group. It was mentioned in chapter 8, that Participant\_21 had to push for information on cancer rehabilitation services; thus, it is possible that the reason for her unmet needs was the insufficient information on available cancer rehabilitation services. Participant\_21 added that she might mention fatigue as an issue at her upcoming last follow-up oncology appointment.

*“I’ve got an appointment with the oncology department in January, I think if I’m still struggling a bit with the fatigue and stuff I’ll just maybe get a bit of advice from them [...].”*  
**(Participant\_21 – person affected by breast cancer)**

Other unmet needs included shortness of breath. Participant\_27 mentioned he had issues with breathlessness. However, he had asthma and COPD, which he mentioned could have been behind his breathlessness.

*“I’m really struggling short of breath. And it doesn’t seem to be getting any better, but I don’t know whether COPD or cancer or... asthma or whatever it is. My... I’m gonna have to go to see my own GP, and see if there’re maybe something a bit stronger than these things I’m taking.”* **(Participant\_27 – person affected by lung cancer)**

His COPD management team was located in a separate hospital from where the Fern Therapy Team was situated. Therefore, Fern might have not been responsible for Participant\_27’s rehabilitation needs. However, from a holistic care point of view, rehabilitation should be everyone’s responsibility, and healthcare professionals should be able to provide level 1 information based on the four level model, or signpost people to adequate services.

In summary, the secondary analysis findings indicate that the exercise classes run by the Willow Therapy Team might have had a positive impact on quality of life and functional outcomes, such as pain, and mobility. Moreover, the qualitative interview findings show that the rehabilitation interventions provided by the Willow and Fern Therapy Teams reduced people’s health needs by improving physical and mental health. While some participants did not regain their level of fitness pre cancer diagnosis, the rehabilitation interventions enabled them to start new exercise regimes and manage their own conditions. This indicates that IPT\_03 and IPT\_04 worked through individualised rehabilitation, physical exercise and psychosocial interventions. However, some interviewees reported to have some unmet rehabilitation needs. This indicates that although the two cancer rehabilitation services helped in reducing health needs, there are aspects of cancer rehabilitation that might not work.

## **10.2 Mechanisms – individualised, tailored cancer rehabilitation interventions**

As part of IPT\_3 and IPT\_4, individualised, tailored cancer rehabilitation, physical exercise and psychosocial interventions were theorised to be the mechanisms that reduce people’s

health needs, improve quality of life and functional outcomes. The findings above showed that these interventions seemed to have worked for some participants. Based on the qualitative interviews with people affected by cancer, the above presented health gains were the result of individualised, tailored cancer rehabilitation.

The individualisation can be observed in the wide range of cancer rehabilitation interventions that the Willow and Fern Therapy Teams offered. The Willow Therapy Team ran hydrotherapy, Tai Chi, and circuits classes. Moreover, within those classes, groups with different levels of difficulty were available, for example gentle and advanced tai chi. The full list of interventions is presented in chapter 9. As people are allocated to exercise groups based on their needs, preferences, and level of fitness, the exercise classes are intrinsically individualised and tailored. Therefore, the mechanism of individualised, tailored cancer rehabilitation and physical exercise cannot be separated.

Moreover, the exercise classes provided by the Willow Therapy Team were continuously tailored based on how people's needs, mobility, and fitness changed. Some participants started their cancer rehabilitation going from easier assisted activities such as hydrotherapy, and slowly progressing to more strenuous exercises in the gym.

*"I went into the... hydrotherapy pool first, which is wonderful. You can move everything with the aid of the water. And then they [Willow Therapy Team] said 'Oh enough of that, now go in the gym.'"* **(Participant\_28 – person affected by breast cancer)**

*"I thought the hydrotherapy was outstanding. [...] I didn't realise how much you could help build you back up again. [...] I sort of enjoy the gym, but I must admit I've struggled... I've struggled more with the gym work than I have with the hydrotherapy, but I've still benefited."* **(Participant\_09 – person affected by prostate cancer)**

Tailoring exercises did not just happen after a 12-week rehabilitation episode, but with each session. Healthcare professionals tried to make sure that everyone did exercise on the day that was suitable for them, and they did not suffer from symptoms or side effects that could potentially be made worse with the wrong movements and activities.

*"You're questioned each week. 'Right? What do I need to know this week?' you know. 'I've got a bad knee.' Hahaha [laughing] So they [Willow Therapy Team] tailor it day by day, you know, to what you can do."* **(Participant\_03 – person affected by breast cancer)**

Based on these individual session by session tailoring, interviewees praised that within the different groups people with different abilities took part and it never caused any issues as they were allowed to work out in their own pace.

*"Today particularly we were people of varying abilities you know, but it doesn't cause a problem. Everybody works at their own rate, so yeah, it's not really a problem."* **(Participant\_30 – person affected by prostate cancer)**

This continuous tailoring helped people slowly increase muscle strength and get used to doing exercises.

*"I'm building up my core strength, you know. Building up the muscles in the legs and the stomach for example and so that is... so it's been beneficial, [...]"* **(Participant\_09 - person affected by prostate cancer)**

*"But also the Tai Chi is so gentle you feel as if you're not using any muscles and you are. [giggling] You are."* **(Participant\_02 – person affected by breast cancer)**

Increased strength led to improved mobility, reducing physical health needs. Additionally, the individualised, tailored exercise classes reassured people in their physical abilities and increased their confidence.

*"I can do this [Tai Chi]. This is something I've done before and I can do it again [...] it was... heartening, that this was something that I could still do. And it was good, it was good. Yeah. Yes, it made you feel a bit less odd."* **(Participant\_03 – person affected by breast cancer)**

Moreover, individualised, tailored exercise classes reduced people's fear regarding doing physical activity with cancer and encouraged people to start managing their own health issues, and promoted active lifestyle with a cancer diagnosis.

*"initially I was... a bit afraid to do anything on my own, but now I've seen what we do, I think I'd be quite happy now to maybe go to you know something... [a public gym] and do the exercises there, so maybe the next couple of weeks."* **(Participant\_30 – person affected by prostate cancer)**

As seen above regarding met health needs, the individualised, tailored exercise classes helped with more than just physical strength and mobility. Attending the exercise classes had a positive impact on people's psychological health. Participants described that going to the exercise classes every week gave them purpose, which brought back a sense of normality in their lives which they lost with their cancer diagnosis. Having a purpose and the new found sense of normality improved people's mental health.

*"Well, it's got me out the house. I don't think I'd do anything or go anywhere otherwise, but no, I think it makes you feel better about yourself, that makes you feel that you can still do things, you can still be normal [...]"* **(Participant\_03 – person affected by cancer)**



*“I probably would be sitting in the chair all day, just worrying. Whereas, it has given me the motivation to get up and let’s do something about it. And... so mentally and physically it’s... it’s definitely... it’s very... very good.”* **(Participant\_09 – person affected by prostate cancer)**

In addition, some people’s mental health and sleeping improved based on the skills that they learnt through Tai Chi. Relaxation and breathing techniques helped people become calm, and these were skills they could use at any time they needed.

*“It’s partly the physical exercise I’m doing, cos I’m properly tired and the breathing exercises that I’ve learned via Tai Chi, so it’s coming together.”* **(Participant\_03 – person affected by breast cancer)**

*“I thought they were very very helpful, because as I say it was... helping you cope with the stress and the relaxation part of it.”* **(Participant\_02 – person affected by breast cancer)**

While the Willow Therapy Team tailored the exercise classes to meet both physical and psychological health needs, the Fern Therapy Team met needs by offering a wide range of cancer rehabilitation interventions targeting specific cancer treatment related side effects. Acupuncture targeted hot flushes, fatigue management aimed to teach skills that would help people deal with tiredness and their changed energy levels. SLTs and dietitians concentrated on swallowing and nutrition.

As seen in section 10.2.1, acupuncture reduced hot flushes for Participant\_18 and Participant\_19. For Participant\_27, the information and advice received from the SLT and dietitian were useful and made him more aware in the ways he was eating and drinking, resulting in reduced swallowing issues.

*“I think because I’m aware of it [swallowing issues] now, I’m a little bit more careful of how I eat it.”* **(Participant\_27 – person affected by lung cancer)**

As mentioned above, the fatigue management met some of Participant\_37’s psychological needs and promoted acceptance of her changed health condition post cancer treatments. Participant\_37 explained that fatigue management worked through providing practical knowledge on how to deal with tiredness and helped change her mindset aiding acceptance.

*“And with the fatigue management there were a few practical tips in there. And like I said I think it helped change my mindset, this whole thing about the battery analogy was like ‘Right, OK, so maybe I do need to take it a bit easier, and maybe I am allowed to sit down in the middle of the day’ which I’ve never before let myself do and stuff like that.”* **(Participant\_37 – person affected by breast cancer)**

While the majority of the interviewed people's health needs were met by the Willow and Fern Therapy Teams, some unmet needs were reported. As mentioned above, issues with hot flushes were reported by interviewees who attended the exercise classes of the Willow Therapy Team, while people who attended the services of the Fern Therapy Team mentioned unresolved psychological and physical issues. For example, Participant\_29 described that talking about psychotherapies broadly did not empower him or provide skills that could help him manage his health needs.

*"It would need to be as I said psychological support which was geared towards empowerment, and not just talking about, you know things broadly..."* **(Participant\_29 – person affected by prostate cancer)**

This is in contrast with Participant\_02's and Participant\_03's account who found that the Tai Chi sessions provided by the Willow Therapy Team taught them skills such as the relaxation and breathing exercises. This difference in people's experiences could indicate that the fatigue management group might need to provide more specific information and they need to help people learn self-management skills. However, as mentioned above, Participant\_29 was quite proactive regarding his health needs. Moreover, he practiced Tai Chi and meditation for several years, which could help him gain skills that other people in the fatigue management group might have not had.

*"I've had a long experience in Tai Chi and in meditation and that's also been very helpful, so I've kind of had a good grounding, really to help me, but still you know, it's... not been easy. But... but probably easier than for some."* **(Participant\_29 – person affected by prostate cancer)**

However, this indicates that the fatigue management group might only cater for people who need basic knowledge, and it does not meet the needs of people who need more specific help. Exploring the contexts below helps understand why the tailoring at the Fern Therapy Team was not successful, and why people did not receive acupuncture and help with their hot flushes at the Willow Therapy Team.

In summary, the mechanism of individualised, tailored exercise classes run by the Willow Therapy Team helped people improve muscle strength leading to increased mobility and reduced physical health needs. Moreover, individualised exercise classes encouraged people to start doing physical activities on their own by reducing their fears regarding exercising with a cancer diagnosis. Individualised, tailored cancer rehabilitation also reassured people affected by cancer in their abilities to perform exercise. The tailored

exercise classes improved people's mental health by providing purpose and a sense of normality, and teaching skills that could help people self-manage stress and sleeping issues. Moreover, the cancer rehabilitation interventions of the Fern Therapy Team helped improving physical and psychological health by raising people's awareness around their health and changing individuals' mindsets. The next section introduces the contexts that inhibited and supported the mechanism of individualised, tailored cancer rehabilitation interventions.

### 10.3 Context – insufficient needs assessment, therapeutic relationships, supportive family, spontaneous peer support, and accessibility issues

In IPT\_3 it was theorised that individualised, tailored care can work if it is based on routine assessment of people's needs, while IPT\_4 hypothesised that service accessibility, and having a trained team can influence the outcome of physical exercises classes. While most people's quality of life improved, and their health needs reduced, some unmet needs still lingered following some of the cancer rehabilitation interventions. This indicates that the contexts of needs assessment, and accessibility might not support individualised, tailored cancer rehabilitation. In chapter 9, issues with the capacity of oncology trained staff have been considered; therefore, it is not discussed in this chapter. However, it must be noted that healthcare professional capacity issues can have a significant impact on meeting people's needs. In this section the influence of the initially hypothesised context of needs assessment is presented first, followed by the context of therapeutic relationships, family, and peer support. Finally, the accessibility of the two Therapy Teams is discussed.

#### 10.3.1 Insufficient needs assessment

Initially, it was theorised that the routine assessment of people's needs can support the provision of individualised, tailored care. Prior to the cancer rehabilitation interventions, healthcare professionals in both the Willow and Fern Therapy Teams conducted assessments specific to their professions and the health issues of the person affected by cancer. For example, swallowing, nutritional, or functional assessments were conducted pre cancer rehabilitation. These assessments were usually standard based on healthcare professionals' training or profession specific assessment tools.

*“So swallowing assessments we’ve got... there isn’t a formalised one, but it tends to be a pro forma going through with your case history, cranial nerves and as you do your training as like no matter where you work it’s a set thing that you kinda do.” (Professional\_02 – SLT)*

*“Ok, so assessment tools we have within occupational therapy there’s one that’s... ours is loosely based on a model called Reed and Sanderson [...]” (Professional\_12 – OT)*

While both the Willow and Fern Therapy Teams provided standard profession specific assessments, the two teams differed in how they conducted needs assessment to identify people’s wider health needs that might need therapeutic input. While the Fern Therapy Team, and some dietitians who worked with the Willow Therapy Team used an informal, verbal approach to map people’s needs, the OTs and physiotherapists in the Willow Therapy Team conducted a more formal, written needs assessment.

#### ***10.3.1.1 Formal, written needs assessment***

As a formal, written needs assessment the OTs and physiotherapists at the Willow Therapy Team asked people affected by cancer to complete a modified version of the concerns checklist (Macmillan Cancer Support 2018). The concerns checklist is a widely used needs assessment tool (Macmillan Cancer Support 2018), which was modified by the Willow Therapy Team to make it less burdensome for people affected by cancer, and to focus it more on the cancer rehabilitation interventions they can provide. The modified version of the concerns checklist is presented in Appendix 29. Using a formal, written needs assessment highlighted that if healthcare professionals had solely relied on a verbal needs assessment, certain issues might have been missed.

*“[...] it [concerns checklist] very quickly showed us that there were key questions that we never asked.” (Professional\_14 – OT)*

Professional\_14 described that conducting this needs assessment served multiple purposes: to provide written proof of the individuals’ needs, and to give an opportunity to people to think about their concerns and express them.

*“We had the documentation then to say this is what matters to the person who’s attending rehabilitation. [...] And I think by sending the holistic needs assessments out to people and asking them to spend a few minutes in preparation for the appointment with family possibly, we were getting a very considered thought process about actually what mattered.” (Participant\_14 – OT)*

While not many people affected by cancer mentioned the assessment as an important aspect of their cancer rehabilitation, Participant\_03 praised that the Willow Therapy Team

conducted a thorough assessment, which helped tailoring and individualising cancer rehabilitation to her needs.

*“But they’re very very good, when they interview you, they find out all these problems, you know they take a good history and it’s basically tailored to you. You know and they keep a very close eye on you. And they’ve got lots of forms they fill in, so it’s a good feeling that somebody else is looking out for you.”* **(Participant\_03 – person affected by breast cancer)**

However, when asked about the questionnaires and forms Participant\_03 had to complete for the assessment she said they were not specific for her condition, but they helped capturing basic health issues.

*“[...] they ask you questions like you know, ‘what can you do? Do you need help with doing things? Pain levels, you know... what you’re doing about it?’ But I think a lot of those are for people who are in slightly different circumstances to me, but I mean I answer them all, but they’re... they... they care a wide range of people you know, so they can’t be specific to what you do, but they get the basics. They get them spot on.”* **(Participant\_03 – person affected by breast cancer)**

Participant\_03’s account indicates that while the assessment provided by the Willow Therapy Team helped tailoring cancer rehabilitation to basic health needs, it might not be able to capture more specific issues. This might explain why some people affected by cancer who attended the exercise classes run by the Willow Therapy Team had some unmet health needs, such as the hot flushes. In addition, the modification of the concerns checklist used by the Willow Therapy Team could have led to issues with identifying certain health needs. While the original concerns checklist contained 71 different health needs or concerns (Macmillan Cancer Support 2018), the modified version contained 18 different issues. Hot flushes were among the issues that were missing from the modified concerns checklist, which could lead to people affected by cancer not mentioning these side effects during assessment. Therefore, it is possible that modifying tested assessment tools leads to missing certain health needs.

Another possible explanation for missing out on people’s needs regarding hot flushes was that Professional\_19 mentioned recent developments in the acupuncture services, meaning they had just started trialling acupuncture in prostate cancer.

*“If you’ve done something specific then we’ll share it so that we can trial it. Like Fern did acupuncture with hot flushes in prostate cancer. Well, they shared that with us [Willow Therapy Team], they shared their results with us, so we can trial that now, cos they showed that that was a benefit.”* **(Professional\_19 – physiotherapist)**

This could mean that the service could have not been offered for people affected by prostate cancer if it did not exist at the time when participants were interviewed. While Participant\_01 was interviewed in May 2018, the interview of Participant\_12 and Professional\_19 was closer to each other with July and August in 2018 respectively. Therefore, it is possible that the acupuncture service could not have been offered to Participant\_12, which is a potential explanation that needs to be considered with regards to unmet health needs.

In summary, formal, written needs assessment has the potential to aid individualised, tailored cancer rehabilitation. However, modifying clinically accepted needs assessment tools might lead to overlooking specific health needs.

#### **10.3.1.2 Informal, verbal needs assessment**

The informal, verbal way to assess needs consisted of healthcare professionals asking general questions from people affected by cancer to identify other wider health needs than what was relevant to their profession. When they identified these health concerns, they referred people affected by cancer to their other AHP colleagues.

*“So, we quite often start with ‘How are you today?’ ‘How are things?’ We don’t go in with ‘How’s your walking?’ ‘How’s this? How’s that?’ And quite often that then disclose, they come out with lots of things before you even got into swallow and communication and we do find quite often that lots of the team could be involved once we sit down with the patient just say ‘Ok, so how are things?’” (Professional\_02 – SLT)*

*“[...] we’re picking stuff up that’s getting missed. And I can only base that on just conversations. So, what does that say? We’re picking up as... an awful lot of stuff that just gets missed. So, I think, because maybe we’re looking at the nutritional aspect and the barriers that we’re actually in the position to encompass... already capturing an awful lot of valuable data. You know, because our assessment is quite... is very thorough [...]” (Professional\_18 – dietitian)*

However, as presented above, Professional\_14 argued that from her experience without a formal, written tool, certain needs could be missed during an assessment where health needs are only verbally probed. This could potentially be a context that resulted in the unmet needs of some people who attended the service of the Fern Therapy Team.

As a reason for not conducting a formal, written needs assessment Professional\_18 argued that a few healthcare professionals had been conducting needs assessment with different

assessment tools. Asking people to complete a new written needs assessment every time they meet a new healthcare professional could lead to questionnaire fatigue.

*"I do see the need for it, it's just... I know there's lots of... stress thermometer out there, so I know there's lots of different tools effectively doing the same thing, that's the problem, yeah. [...] That's my only worry is that if everybody's asked the same thing repeatedly it will... gonna develop a bit of fatigue."* (Professional\_18 – dietitian)

This raised questions on who should be providing needs assessment.

#### **10.3.1.3 Needs assessment and coordination of cancer rehabilitation services**

Professional\_18 questioned if AHPs were best positioned to provide needs assessment for people affected by cancer. She expressed that meeting people's needs did not only consist of conducting the needs assessment but being able to signpost people affected by cancer to appropriate services. However, signposting required knowledge on available services, and resources which might not be available for AHPs. Therefore, Professional\_18 suggested that meeting people's needs should be coordinated by other healthcare professionals.

*"[...] we [AHPs] can't be catch all for everything and know everything out there. You know, to go with HNA [holistic needs assessment] you need the resources, you need... lists of local services, so you can signpost people to the full list. I mean... this... is... it's hard to keep up to speed with what's out there, but somebody needs to coordinate that for us to get it right."* (Professional\_18 – dietitian)

Professional\_18 reasoned that healthcare professionals who follow the person through the whole cancer pathway would be best suited to provide needs assessment and coordinate care. These healthcare professionals should be the keyworkers.

*"I suppose HNA, you know, somebody that's following people throughout their journey, you have to ask question that they are the better... the keyworker is the better people to kind of perform the HNA."* (Professional\_18 – dietitian)

Moreover, Professional\_18 said that GPs and cancer specialist nurses were the most suitable for the keyworker role.

*"Whereas I think specialists... it's now increasingly recognised that maybe specialist nurses within certain areas after... or GPs are the better people for actually maybe being care wo... the keyworkers"* (Professional\_18 – dietitian)

Keyworker allocation from the perspectives of people affected by cancer had varying success. Some people affected by cancer had keyworkers allocated who they knew they could contact when needed.

*“Yeah, keyworker is [Nurse]. He’s... I don’t see him very often. But I’ve got his card, it’s always in my drawer and he’s... you know, if I do have any concerns, he’s on the other end of the telephone. I haven’t had to bother him yet, touch wood.”* **(Participant\_30 – person affected by prostate cancer)**

However, some people affected by cancer reported that they often did not know who their keyworker was, and usually met several people throughout their cancer care.

*“In the [hospital] I had one nurse, sometimes I’d see another one, but mainly the same nurse. On a second operation it was a different nurse, still lovely [...]”* **(Participant\_28 – person affected by breast cancer)**

Participant\_37 for example mentioned that she was referred to several keyworkers through the course of her treatments, causing confusion.

*“And then when I was going through treatment in Fern, I had a keyworker, but I found it quite confusing, because every time I... you know, you go to... before your chemo you go to clinic. Every time I went I pretty much saw somebody different and each time they said ‘Oh, I’m your key worker.’ So both times three people had said that they were my keyworker, I was starting to get a bit confused.”* **(Participant\_37 – person affected by breast cancer)**

This problem with keyworkers could indicate that issues might exist in the coordination of cancer rehabilitation interventions, leading to unmet needs. Moreover, cancer rehabilitation coordination might have a potential association with the context identified as lack of routinely provided cancer rehabilitation services presented in chapter 8.

In summary, there was no gold-standard way of providing needs assessment, potentially leading to missed needs. Therefore, while having thorough needs assessment could be a supportive context to the mechanism of individualised, tailored cancer rehabilitation, insufficient needs assessment inhibits the provision of fully individualised interventions. Moreover, Professional\_18 argued that keyworkers should conduct needs assessment, and AHPs may not be best placed to become keyworkers. Moreover, some people affected by cancer had issues in the ways that keyworkers were allocated. This could indicate potential service coordination issues that could lead to problems with referrals to cancer rehabilitation. However, assessment of health needs is not the only context that influenced the mechanism of individualised, tailored cancer rehabilitation.



### 10.3.2 Therapeutic relationships

Issues with conducting needs assessment was not the only context that influenced the mechanism of individualised, tailored cancer rehabilitation. Having knowledgeable and caring professionals looking after people affected by cancer and leading the exercise classes or the fatigue management group was a supportive context for individualised, tailored cancer rehabilitation interventions. Healthcare professionals' caring personality aided trust building leading to more open conversations with people and more tailored cancer rehabilitation.

*"She's a very caring person. Empathetic. And you feel you can talk to her. You know, if you're having a bad day, like when I'm in like... when I was having those cluster migraines you know, you could tell her anything. I was having them 'Oh, what can we do?' you know, I said 'Well it's just a question of dark glasses and sitting down, you know.' But no, but you know you could tell her, you have to tell her basically, because then she can tailor what she does to you specifically, which is good."* **(Participant\_03 – person affected by breast cancer)**

Some participants developed a strong connection with the healthcare professionals leading the exercise classes which potentially enhanced the impact of the exercise classes through emotional support.

*"I know they're physiotherapists. To me they aren't physiotherapists, they're friends of mine that I come and see on a regular basis. And I think that has helped me far more than the... than simply doing the hydrotherapy."* **(Participant\_10 – person affected by prostate cancer)**

This relationship helped people open up about sensitive issues, such as sexual problems, aiding tailored care and meeting health needs.

*"I feel any problem, no matter what, if I've got a problem, I can discuss it with her [AHP]. She's helped me. I had a problem with sex, she's referred me to a sexual therapist."* **(Participant\_10 – person affected by prostate cancer)**

Moreover, it was more important for Participant\_10 to have his review with the healthcare professional he built a relationship with than the review itself.

*"I said to her 'Look you know, don't get me wrong I'm sure the other [AHP] is fine, but I don't know her, I've never met her. I know you, I feel I can talk to you. I would prefer to see you.' [...]"* **(Participant\_10 – person affected by prostate cancer)**

In addition to building relationships with the healthcare professionals that aided the identification of health needs and tailoring care, people affected by cancer reported that

healthcare professionals were watching them closely, and always spotted when they had health issues and either adapted exercises for them or advised them not to continue on the day.

*“[...] they [Willow Therapy Team] watch you all the time and they know when you’re right and when you’re wrong and that’s what’s... That’s what is important.” (Participant\_01 – person affected by prostate cancer)*

*“The girls doing the Tai Chi classes are really, really good, and they’re very attentive, because they’re watching you all the time and one day I was feeling a bit light headed and I didn’t think I was showing it at all. And I said I was fine, and the next thing one of them was next to me saying ‘Are you Ok?’ And I thought ‘How did you know?’” (Participant\_02 – person affected by colorectal cancer)*

Additionally, healthcare professionals aided people to try new things. They supported and enabled participants to do the exercises. For example, Participant\_28’s account shows that the healthcare professionals helped her fight her fear regarding the exercise classes, which enabled her to attend the hydrotherapy and circuits classes and increase her strength.

*“Even when in the pool first I had ‘Oh, no’ I was a bit shy, I didn’t want to. But their reassurance and their coaxing me to do things. I think that’s what was the best thing for me. Just putting my trust in them really. I mean it was wonderful.” (Participant\_28 – person affected by breast cancer)*

These accounts of people affected by cancer show that good relationships built on trust with caring healthcare professionals can aid the identification of health needs, and the tailoring of cancer rehabilitation. Moreover, healthcare professionals provided emotional support for people affected by cancer. However, building a too strong relationship could potentially be an issue with regards to discharging people from the services. Professional\_14 mentioned that they had difficulty discharging people, as the therapeutic relationships were not managed, leading to people not self-managing their health issues.

*“[...] we still hold on to people for too long, we still molec... cuddle them for too long. And people like that. They don’t like being let go, but I think part of the problem is that the longer we keep them, the more they like it, so the harder it is to let go. Whereas if we can do the least amount of support at the right time, so that people can stay on their own two feet, then that we don’t breed dependency.” (Professional\_14 – OT)*

These discharge issues are supported by the secondary analysis, as there were people in the database, who had 12 rehabilitation episodes reported, indicating several months of cancer rehabilitation by the Willow Therapy Team. Professional\_14’s account and the secondary analysis indicate that if therapeutic relationships are not managed well,

individualised, tailored care could lose one of its outcomes, namely self-management. However, people affected by cancer who were interviewed for this PhD study seemed to understand that attending the exercise classes of the Willow Therapy Team was temporary. Even though they were sad it was finishing, they understood that they could not depend on the services. Participant\_01 used a lifeboat metaphor to describe cancer rehabilitation, indicating that being discharged from the exercise classes of the Willow Therapy was a necessary part of the cancer pathway and recovery. However, he mentioned that there were people who kept coming back to the Willow Therapy Team. This indicates that therapeutic relationships might have been better managed for Participant\_01 and the interviewees in this study than for others.

*“I miss not being there, but that’s also a bit like... that’s not getting out of the lifeboat, isn’t it? On to dry land, you don’t... you know you’re gonna miss being in the lifeboat, but come on... I mean there’s a whole journey to be left. I know some people who go around in circles there [Willow Therapy Team]. Some of them go to gym and they finish up back in there, cos they need that support.” (Participant\_01 – person affected by prostate cancer)*

### 10.3.3 Supportive family

Social support, particularly support from people’s family was found to be an important context enabling individualised, tailored cancer rehabilitation. The family could often provide practical support to help attending the cancer rehabilitation services or become a source of motivation. For example, Participant\_28 mentioned that her husband drove her to the exercise classes every time.

*“Because he drops me off and then he marches around [Park] for his exercise, and it works out well. So, there’s no difficulty with getting there. There’s no difficulty with being picked up after. It’s just easy. Easy for me.” (Participant\_28 – person affected by breast cancer)*

Without his support she would not have been able to attend the cancer rehabilitation services, which could have impacted on her quality of life and health needs.

In addition to driving, having a physically active family could be a supportive context, as people affected by cancer often want to join their family members in physical activities, which serves as a source of motivation. Participant\_12’s partner was very active physically, regularly cycling and swimming, which motivated Participant\_12 to learn to swim properly to join her. Motivation to join her in the pool and the skills that he learnt at the hydrotherapy run by the Willow Therapy Team enabled him to start thinking about exercising outside of the cancer rehabilitation interventions.

*"My wife's a beautiful swimmer, just watching that, oh, God, she just glides up and down. She does 40 length on a Sunday morning. And she's 64. Just all these lengths. I would love to go in there and join her. So I'm gonna try that next, that's all come from the pool."* (Participant\_12 – person affected by prostate cancer)

Participant\_10 mentioned that his son's partner was a nutritional specialist which motivated him to stay active and lose weight to impress her.

*"And his girlfriend is a sports nutritionist hahaha [laughing], so I've been told I've gotta weight... lose weight before she comes over. Which I'm doing, I'm on track in that, that's OK."* (Participant\_10 – person affected by prostate cancer)

These extracts show that supportive family can help the person with cancer to attend cancer rehabilitation and motivate the individual to become active, indicating that family can be a supportive context.

#### 10.3.4 Peer support

Another important part of social support was peer support. Peer support during cancer rehabilitation interventions, such as exercise was spontaneous. "Spontaneous peer support" meant that people's aim was not to attend a formal peer support group, where they might sit around and share their experiences, but to exercise (Fox et al. 2019). However, during the exercise people did provide support for each other. For example, this "spontaneous peer support" provided reassurance for new exercise participants and eased their fears.

*"We had a new girl [...] in class in this morning, she was terrified. I have said 'You've got nothing to be terrified about, you know, these are things you can do, you could pace yourself, do whatever you can and if you can't, do have a sit down with a glass of water.' You know. So, we all support... we are like our own support, you know we help each other."* (Participant\_03 – person affected by breast cancer)

Moreover, as presented in the above section, the mechanism of individualised, tailored cancer rehabilitation gave purpose for people and provided a sense of normality which was partially induced by meeting other people, and socialising before, during, and after the rehabilitation interventions.

*"I've spoken to everyone that I've done hydrotherapy with, you come out of pool, you get dried, and then you get dressed and you chat and everyone I can guarantee you, every single one says exactly the same thing. I... it's the social side."* (Participant\_10 – person affected by prostate cancer)

*“You get to know people, and you chat and everybody wants to know what the consultant say last week and how are you doing now, and everybody supports everybody else, so that... there’s that side of it as well. I can’t... I don’t know, I’m not finding the right words really to explain. It’s a very very good thing anyway I think. It’s not just the physical, it’s not just the relaxation. It’s a support group as well at the same time.”* **(Participant\_02 – person affected by colorectal cancer)**

In addition to the exercise classes, “spontaneous peer support” was detectable in the fatigue management group. Participant\_29 who did not enjoy formal peer support groups praised the fatigue management groups, as it felt like a more relaxed environment.

*“I want to, as much as possible get on with living my life and not be connected to an organised peer support group. [...] But the peer support during the cancer Fatigue group I found that very good, because it was more relaxed, more informal and it wasn’t on kind of going on outings, [...]”* **(Participant\_29 – person affected by prostate cancer)**

However, Participant\_37 mentioned that while she enjoyed the fatigue management groups, she found that the age gap between her and the other participants was an issue, as everyone in the group was older than her. While her main concerns were around return to work and caring for her children, all the other group members were retired with different needs from hers. Therefore, she felt misplaced in the group.

*“[...] everybody else in the group was considerably older than me, so they were all retired. So, I was the only one with young children. I was the only one who’s still working... so in that respect I was a bit like ‘Oh, why am I here?’ [...]”* **(Participant\_37 – person affected by breast cancer)**

Participant\_21’s account supports that the lack of age-matching in psychosocial interventions might be an issue. While Participant\_21 did not attend the fatigue management groups, she took part in an acceptance and commitment therapy group led by the psychology department of the cancer centre where the Fern Therapy Team was located. Participant\_21 liked the group format, although she mentioned that having more people in the group with similar age would have been beneficial.

*“[...] all the other ladies on it were a lot older than me. So, I find sometimes that the sort of things I wanted to talk about were very different to them, because a lot of them had grown up children and grandchildren, and they were just at a very different stage in their life compared to me. So, I think, I did put on the feedback form that it would be nice if they could do sessions for young, like trying... you know, age match the sessions, so it was more younger people, so you’ve got similar... a similar outlook.”* **(Participant\_21 - person affected by breast cancer)**

Lack of age-matched peer groups could lead to insufficient emotional support and information exchange that would result in unmet psychological health needs and self-management issues.

### 10.3.5 Accessibility issues

People who attended the exercise classes run by the Willow Therapy Team raised issues with the accessibility of the cancer rehabilitation services. One of the biggest issues was parking. People affected by cancer almost uniformly reported that parking by the hospital where the Willow Therapy Team was located was difficult and time consuming. Many people affected by cancer had to leave their home an hour earlier just to be able to find a parking space, as this task often took up to 45 minutes.

*“The biggest problem and the most stressful problem for me was actually finding a car parking space. Cos when you got... you’ve got like a set time of either, it would have been something like 9.30 or 10.30 in the morning for the hydrotherapy, the car park was generally very full at that time. So, I had to leave my home an hour earlier than I would normally and sometimes it would take 45 minutes or so to find a car parking space, which is crazy, absolutely.” (Participant\_09 – person affected by prostate cancer)*

Participant\_02 also described it as stressful, and she mentioned that at one time she had to rely on the mercy of the parking security officer. She had to circle around for parking space multiple times, but she could not find one. In the end the security officer let her park in a disabled space, so that she would not miss the exercise class.

*“[...] often you drive around and round and one day I was getting so desperate, because I was late for class and I was getting a bit agitated and I said to the man in the little box when I went around for the fourth time [...] ‘Look, I can’t find anywhere to park’ I said ‘My appointment time is...’ said ‘is already gone, and I’m starting to get really stressed out’ and I said ‘You know’ I said ‘This disabled space is...’ I said ‘with no one in them’ ‘Well, use one of those’ he said to me ‘You’re gonna have to... Off you go’ he said.” (Participant\_02 – person affected by colorectal cancer)*

Moreover, Participant\_10 said that trying to find parking in the hospital made access to the exercise classes a chore.

*“[...] whether they could put a multi-storey carpark in, I don’t know. But it’s crazy... it’s just makes it a chore, rather than a... but you know, a fun thing to do like.” (Participant\_10 – person affected by cancer)*

While this issue with parking did not impede interviewees from attending the exercises classes, stressful parking potentially could drive other people away from accessing cancer rehabilitation services.

Other issues with accessing cancer rehabilitation services were travelling. This was a problem that potentially impacted on both the Willow and the Fern Therapy Teams. People affected by cancer expressed that cancer rehabilitation services closer to their homes would be beneficial.

*“[...] I only wish that some of the... more local hospitals could do it [exercise classes] as well [...]”* (Participant\_09 – person affected by prostate cancer)

Participant\_02’s account particularly highlighted the issues with travelling when someone has cancer. She described that healthcare professionals often worried about her getting home, especially on days when Participant\_02 was feeling very tired.

*“[...] it is hard when you’re struggling and tired all the time to travel an hour there and do it and an hour back. And you know I was driving myself in the end and a couple of times I had to be sent home, because they said they were concerned about me driving home that I got some... because I was tired, I was getting very tired, so I had to leave early to drive back.”*  
**(Professional\_02 – person affected by colorectal cancer)**

While people who were interviewed for this study continued attending cancer rehabilitation regardless of the accessibility issues, travelling and the lack of services closer to individuals’ home who might not be as motivated as Participant\_02 could potentially lead to people not seeking help and living with health issues.

In addition to the parking and travelling issues, the timing of the Willow Therapy Team exercise classes was a potential problem. Participant\_09 described that if he had not retired when he learnt about his cancer diagnosis, he could not have attended the exercise classes run by the Willow Therapy Team due to the timing of the session. All sessions were provided between 9.00 am and 5.00 pm, when most working age people are in work.

*“[...] if I had... could have remained working, it would have been very difficult to schedule in then. In fact it would have been impossible, because of the time of the hydrotherapy and also the gym work would have clashed with my working day, so I would never be able to do it.* **(Participant\_09 – person affected by prostate cancer)**

People who work throughout their cancer treatments or need to return to work might not be able to access the exercise classes, leaving them with unmet health needs. This is

supported by the Willow participants' characteristics who took part in this PhD study, as all of them were retired.

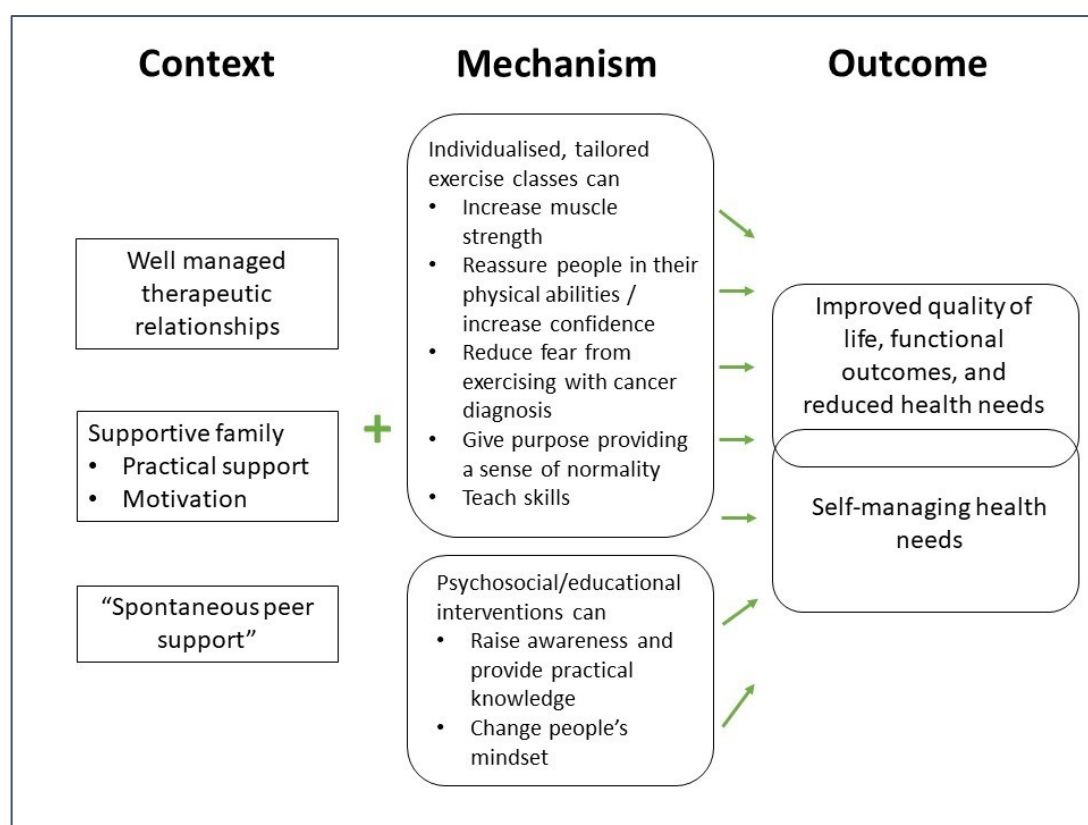
## 10.4 Refined CMO\_3

IPT\_3 and IPT\_4 developed prior to data collection and testing suggested that individualised tailored cancer rehabilitation, physical exercise, psychosocial and educational intervention can help reduce people's health needs and improve quality of life and functional outcomes. Based on the findings of the data collection and analysis, people's quality of life and functional outcomes, such as mobility and pain, improved following physical exercise classes provided by the Willow Therapy Team. Moreover, physical, and psychological needs of people affected by cancer were met for most participants. However, certain unmet needs and health issues were reported by people affected by cancer, indicating that cancer rehabilitation interventions did not fully work as initially theorised. First, based on the interview findings, the mechanism of individualised, tailored cancer rehabilitation and the physical exercise classes were amalgamated. This integration was performed, because the interventions offered by the Willow Therapy Team were intrinsically tailored through the different difficulty levels based on people's needs, preferences and functional status.

In addition to the change in the mechanisms, numerous contexts were identified that supported and inhibited the provision of individualised, tailored cancer rehabilitation. Contexts that supported individualised, tailored cancer rehabilitation interventions were well managed therapeutic relationships, supportive family, and "spontaneous peer support". These contexts acted in different ways increasing the impact of cancer rehabilitation interventions. Well managed therapeutic relationships helped tailoring cancer rehabilitation, as people more openly discussed issues with healthcare professionals who they trusted and could rely on. The context of supportive family was found helpful in two ways. They provided practical support, such as driving, which enabled people to get to cancer rehabilitation. Moreover, family often provided motivation for people to manage their health issues and become physically active. "Spontaneous peer support" was also an important context as it provided a relaxed informal support for people affected by cancer, and through the social interactions helped to restore a sense of normality that might have been lost with the cancer diagnosis. Figure 19 shows the new refined CMO\_3 which highlights the contexts that made the cancer rehabilitation interventions work.



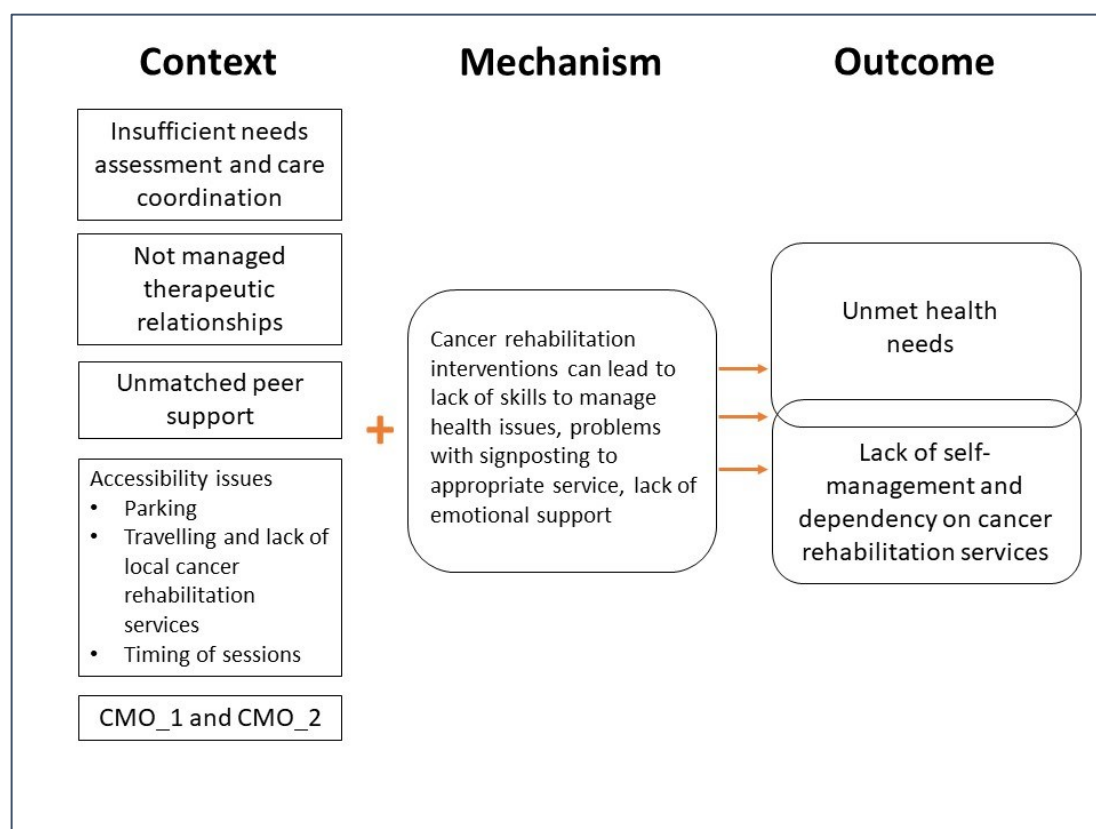
Figure 19 Refined CMO\_3



In the IPTs it was also theorised that self-management was part of how the mechanism worked. However, improved quality of life and functional outcomes, and reduced health needs were not an endpoint for every person affected by cancer. Some people had to live with health issues that needed constant management. For these people, self-management was the outcome, which was achieved with individualised, tailored care that increased people's confidence, reduced their fears, and provided them with the skills that they needed to manage their condition. Moreover, the outcomes of improved quality of life, and self-management were depicted on Figure 19 as partially joined together because cancer rehabilitation interventions could lead to improved quality of life, self-management, or both.

As mentioned above, some people affected by cancer who attended the services of the Willow and Fern Therapy Teams had unmet health needs. These were the result of insufficient needs assessment and care coordination, not managed therapeutic relationships, unmatched peer support, accessibility issues, and the outcomes of CMO\_1 and CMO\_2. The refined CMO\_3 which shows the contexts inhibiting individualised, tailored cancer rehabilitation provision are presented in Figure 20.

Figure 20 Alternative CMO\_3 showing contexts inhibiting individualised, tailored cancer rehabilitation



As seen above there was not gold-standard way to conduct needs assessment, which could have led to not identifying cancer rehabilitation needs. Cancer rehabilitation services cannot be tailored to people's needs if those needs are not identified. In addition, coordination issues were found regarding cancer rehabilitation services, as healthcare professionals argued that keyworkers should be conducting needs assessment, although people affected by cancer had issues with keyworker allocation, as many people had no keyworker or several keyworkers leading to confusion.

Therapeutic relationships could also be an inhibiting context if not managed. This lack of management could lead to people not having the skills to deal with their health condition and they constantly depended on healthcare services. Therapeutic relationship management issues included not setting boundaries to the services, and potentially overprotecting the person affected by cancer.

Unmatched peer support referred to the issue reported by younger people affected by cancer, who found the lack of age matching in psychosocial and educational interventions led to insufficient emotional support, as older people could not necessarily relate to issues

of caring for children or return to work with fatigue. Moreover, accessibility issues were identified which could have led to people not engaging in cancer rehabilitation interventions. Finally, the outcomes of CMO\_1 and CMO\_2 could potentially lead to unmet health needs. In CMO\_1 highlighted that fluctuation was detectable in cancer rehabilitation service uptake and referrals due to insufficient information. If people do not access cancer rehabilitation services, because they do not know they exist, that could lead to unmet health needs. Moreover, some people affected by cancer mentioned that exercise classes could have been more intensive or complimentary therapies could have been offered. The reason for these issues stem from the outcome of CMO\_2, as it can be challenging to meet people's needs if there are no staff capacity to provide more frequent exercise classes or complimentary therapies.

## 10.5 Conclusion

This chapter introduced the realist data testing of IPT\_3 and IPT\_4. The findings indicate that individualised, tailored cancer rehabilitation interventions can help improve quality of life and functional outcomes and reduce health needs. However, some people affected by cancer reported unmet needs indicating that certain contexts inhibited cancer rehabilitation. These contexts included insufficient needs assessment, unmanaged therapeutic relationships, unmatched peer support, accessibility issues, and issues with service uptake and referrals and staff capacity that could led to people having unmet needs. Based on these findings a new CMO\_3 on how cancer rehabilitation interventions work was developed, followed by an alternative CMO\_3 which showed what led to people's unmet health needs. In the next chapter, the findings of this PhD study will be discussed in the light of the wider literature.

## Chapter 11: Discussion

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Following the introduction of the findings in the previous chapters, here the findings are summarised and discussed considering the wider literature. Following the discussion of the CMOs in the light of the wider literature, reflection on this PhD study is presented. I reflect on the secondary analysis and the use of routinely collected data, the recruitment of interview participants, the qualitative interviews, and my overall development as a researcher throughout this PhD. Then, the strength and limitations of the study are summarised, followed by the implications of the study to clinical practice. Moreover, the impact of the COVID-19 pandemic on the two cancer rehabilitation services is briefly discussed. Finally, the chapter and the thesis are concluded.

### 11.1 Summary and discussion of the findings in the light of the wider literature

The previous chapters introduced the complex findings of this PhD study. However, it is important to discuss how these findings relate to the aim and research question. This PhD study had a broad aim and research question to allow for the exploration of the different mechanisms and contexts that result in the outcomes of the cancer rehabilitation services in South Wales. The broad aim was to investigate what works in two cancer rehabilitation services, for whom, in what circumstances and how. The research question reflected this aim, and the broad question of realist evaluation: what works in cancer rehabilitation services, for whom, in what circumstances, and how? Realist evaluation aims to investigate what interventions work, for what population, in what contexts and how interventions result in outcomes through the interactions of contexts and mechanisms. The more focused interventions that this study investigated were information provision, training needs assessment and training of healthcare professionals, and individualised, tailored cancer rehabilitation interventions, such as the exercise classes run by the Willow Therapy Team and fatigue management groups led by the Fern Therapy Team.

Initial programme theories (IPTs) were developed with these interventions and were tested with qualitative data analysis and quantitative secondary analysis. Based on the IPTs three main context-mechanism-outcome (CMO) configurations were developed. In addition to the main CMOs, each main CMO had alternative CMOs as data collection identified new

mechanisms and context that influenced the outcomes of cancer rehabilitation services. The findings based on these CMO configurations indicate that cancer rehabilitation, provided in the form of exercise classes, educational courses, and one-to-one sessions with an AHP, can have a positive impact on people's quality of life, functional outcomes, and health needs. However, several contexts inhibited cancer rehabilitation service provision. Some contexts directly, while others indirectly affected service provision via their impact on the mechanisms of information on and referral to cancer rehabilitation services, and healthcare professionals training. These contexts include lack of consensus on what cancer rehabilitation is, the wider MDTs lack of knowledge and time, the prevailing medical model, no routine care provision, communication breakdown between people and professionals, non-use of the four level model, needs assessment and care coordination issues, management of therapeutic relationships and inaccessibility of services.

Three main abstract theories were used in this PhD study to inform the development of IPTs and help understand how cancer rehabilitation could work. While the findings indicate that cancer rehabilitation does not work to its full potential, discussing the mechanisms and contexts presented in this thesis with regards to the abstract theories can help further understand service provision issues. First, cancer rehabilitation service delivery is discussed in relation to self-determination theory and patient activation, then from the perspective of the biopsychosocial model.

#### **11.1.1 Autonomy**

Self-determination theory holds that the three psychological needs of autonomy, competence, and relatedness needs to be satisfied in order to achieve lasting behaviour change and improved quality of life (Ryan et al. 2008). Autonomy has been considered a prerequisite, as people need to engage with behaviours volitionally. In this PhD study, autonomy initially was considered with regards to people's engagement with cancer rehabilitation and service uptake (section 4.5.1). It was hypothesised that people will only engage with cancer rehabilitation if they have a more autonomous motivation to do so and their perception of the interventions are supportive. The findings indicated that regardless of people's perception of cancer rehabilitation, the interviewed participants still engaged. Regarding autonomous motivation, majority of the participants, particularly the subgroup attending the exercise classes provided by the Willow Therapy Team, had an active lifestyle prior to their cancer diagnosis. This could indicate that these participants had autonomous

motivation to engage with exercise-based cancer rehabilitation prior to attending their first session. Thus, cancer rehabilitation did not need to support their autonomy to help adherence.

Analysis of the routinely collected data showed missing data due to people disengaging from the services. While several reasons could explain why someone disengaged from the cancer rehabilitation services, including health deterioration or death, it must be considered that one possible explanation could be that these individuals did not have autonomous motivation and their autonomy was not supported to start the internalisation of exercise-based cancer rehabilitation. Thus, their motivation to try exercise-based cancer rehabilitation in the first place might have been due to externally regulated processes, such as feelings that they were expected to go by their wider MDT. However, investigation of why people disengaged from the cancer rehabilitation services was out of the scope of this PhD study. Future research could focus on investigating subgroups of people affected by cancer who disengaged or did not engage with cancer rehabilitation services.

#### 11.1.2 Competence and Patient activation

In self-determination theory, competence refers to the skills and confidence needed for behaviour change (Ryan et al. 2008). In this sense, patient activation is related to self-determination theory, as patient activation holds that skills, and confidence are needed for people's active engagement in their own care (Hibbard and Gilburt 2014). Developing competence and patient activation are the main mechanisms that the two cancer rehabilitation services focused on to help people manage their cancer related health issues. Based on the findings of this PhD study, cancer rehabilitation services were the most successful when they helped people gain new skills, and confidence via individualised, tailored care. Both patient activation and self-determination theory supports that people's need for competence can be satisfied by tailoring interventions to the level they are at (Ryan et al. 2008, Hibbard and Gilburt 2014). Moreover, qualitative studies discussed in chapter 3 also support that individualised, tailored care is a facilitator of cancer rehabilitation (Lavalleyé et al. 2019, Fox et al. 2019, Granger et al. 2017).

The wider literature also supports that individualised cancer rehabilitation contains an element of choice. Ryan and Deci (2000) discussed that providing choice for people affected by cancer can support the satisfaction of autonomy, thus the cancer rehabilitation services,

who offer choice in their interventions, may have more success in engaging people affected by cancer. In that sense, the Willow Therapy Team offered a choice in the range of exercise classes offered. However, the inflexible timings of sessions, which were provided during usual working hours between 9.00 am and 5.00 pm, potentially could limit choice and exclude people affected by cancer who had to return to full-time work.

The above discussion points considered building competence and supporting autonomy once people have already engaged with the services. However, building competence and activating people affected by cancer starts prior to the first appointment. The findings of this PhD study showed that there were variations in how people learnt about cancer rehabilitation services, often due to the insufficient information and lack of referrals provided by the wider MDT. This led to potential fluctuations in cancer rehabilitation service uptake and delayed support for people affected by cancer. Ohlsson-Nevo et al. (2019) argued that if people did not receive information about the value and benefits of cancer rehabilitation, they would not have the competence to engage with cancer rehabilitation. Thus, raising people's awareness about available cancer rehabilitation services could potentially satisfy the need for competence, and initiate patient activation by providing knowledge for people to make a decision about how they want to manage their cancer treatment related side effects.

In addition, Ohlsson-Nevo et al. (2019) found that people who attended higher education were more likely to engage in cancer rehabilitation than someone with less education. Ohlsson-Nevo et al. (2019) argued that people with higher education degrees are more likely to have knowledge about interventions that could help them, thus indicating more competence or activation. Moreover, Ohlsson-Nevo et al. (2019) mentioned that people, who had higher education levels, were "information seekers" trying to learn about services that could help them when information was not provided by their healthcare teams. While this PhD study did not examine people's education levels, evidence was found in qualitative interviews that people often had to actively seek or push for information about cancer rehabilitation services. The need to push for information could mean that people who are less vocal about their cancer treatment related side effects might miss out on services that could help them.

While Ohlsson-Nevo et al. (2019) considered information seeking behaviour as related to competence, it is possible that these people had autonomous motivation to engage in

cancer rehabilitation services and only needed more knowledge (competence) to join. Thus, meaning that perceived level of autonomy had more to do with their information seeking behaviour than their education level. Ohlsson-Nevo et al. (2019) also equated higher education levels with the satisfied psychological need of competence, while in patient activation there is no significant relationship between activation level, education, and socio-economic status (Hibbard and Gilbert 2014). Future research could investigate the link between autonomous motivation, competence, patient activation, and people's education to see if healthcare professionals not raising awareness of cancer rehabilitation services could negatively impact people who have lower education levels.

The lack of information in this PhD study not only affected cancer rehabilitation service uptake, but people also experienced stress and uncertainty due to not knowing how to deal with their cancer treatment related side effects. This is in line with self-determination theory, which claims that people's mental health can be affected if the three psychological needs are not satisfied (Ryan et al. 2008). In this thesis, based on the data available, the lack of need fulfilment for competence led to psychological symptoms. Moreover, research in cardiac rehabilitation demonstrated that satisfying the need for competence led to improved well-being (Rahman et al. 2015), thus indicating that competence might be more important than initially hypothesised by self-determination theorists.

While so far competence achieved through individualised care and information provision was discussed with regards to people's engagement with services (uptake) and their mental health, it is important to mention longer term behaviour change. Both self-determination theory and patient activation holds that the fulfilment of the three psychological needs can help the maintenance of a behaviour change. Cancer rehabilitation does not only focus on helping people improve their quality of life and functional outcomes, but it tries to aid people in the long-term management of their cancer related health issues by providing skills and competence. In this PhD study evidence was found that people planned to carry on exercising after their cancer rehabilitation episode ended, or to apply knowledge gained at the fatigue management groups to their everyday life. However, conducting a follow-up to see if these behaviours were maintained long term was out of the scope of this PhD study. Future research could focus on longitudinal studies that could investigate if cancer rehabilitation led to long-term behaviour change.



### 11.1.3 Relatedness

The third psychological need that have to be satisfied for behaviour change is relatedness, referring to supportive relationships (Ryan and Deci 2000). In this PhD study, findings indicate that cancer rehabilitation works best when the person affected by cancer has a supportive family, experiences peer support, and have a well-managed therapeutic relationship. These findings support the evidence in the wider literature on the importance of a supportive environment, whether that is family or friends (Granger et al. 2017, Yannitsos et al. 2020), patient-professional relationships (Browall et al. 2018, Lavalée et al. 2019), or peers attending cancer rehabilitation groups (Lavalée et al. 2019, Midtgaard et al. 2015). Moreover, while in the literature autonomy is often considered as one of most important psychological needs necessary for maintenance of a behaviour change, Peddle et al. (2008) found that relatedness and competence were the most significant predictors of people internalising a new behaviour. Outside of the field of cancer rehabilitation, Mack et al. (2017) found that fulfilment of relatedness via a community based exercise group for people with osteoporosis, added to the positive effect and success of the intervention.

However, it must be mentioned that lack of relatedness or unbalanced support could lead to the thwarting of a new behaviour. In the wider literature, overprotective family (Browall et al. 2018, Lavalée et al. 2019), and issues with therapeutic relationships (Wilkinson 2020) can act as a barrier to engaging in cancer rehabilitation and self-managing cancer treatment related side effects longer term. In this PhD study, evidence was found to issues with managing therapeutic relationships, which often bred dependency on cancer rehabilitation services and inhibited the adoption of self-management behaviours. Wilkinson (2020) suggested that healthcare professionals need to work on the constructive dissolution of therapeutic relationships to help people maintain self-management after cancer rehabilitation programmes end.

In summary, in this PhD study evidence was found that the satisfaction of competence, and relatedness can support engagement in cancer rehabilitation services and could potentially lead to improved mental health and adoption of new behaviours. There is less evidence available on how autonomy is fulfilled through cancer rehabilitation, and there is a possibility that people who engaged in cancer rehabilitation might have already possessed autonomous motivation to start attending the exercise group or manage their fatigue. This could mean that there is a population who may be underserved as they do not receive

support that could support the satisfaction of the psychological need for autonomy. However, further research is needed with the involvement of people who did not attend any of the two cancer rehabilitation services, as it could potentially highlight factors not considered in this thesis.

#### 11.1.4 Biopsychosocial model

The biopsychosocial model was used in this thesis to understand how cancer rehabilitation services work, particularly as cancer rehabilitation, as discussed in chapter 2, considers multiple elements of health, and functioning, including physical, psychological, social, and economical. However, findings of this PhD study indicate that the prevailing medical model is a context inhibiting referrals and information provision regarding cancer rehabilitation. As opposed to the biopsychosocial model, the biomedical model mainly focuses on the physical components of health, without considering psychological and social determinants (Engel 1977). Many healthcare professionals in this PhD study reported that they felt their work was treated as an extra or an add on, and focus was on curing the tangible, physical manifestation of cancer. This biomedical approach led to insufficient information about cancer rehabilitation services provided by the wider MDT, leading to people affected by cancer not learning about cancer rehabilitation and uptake issues.

These results are in line with the wider literature, which shows that the medical model often manifested in the prioritisation of treatments and medical procedures compared to cancer rehabilitation (Olsson Moller et al. 2020). Moreover, Bourke et al. (2018) found that the conservative thinking of certain medical professionals and “traditional values” were a barrier to the implementation of exercise classes specific to people affected by cancer, even though exercise provision for people affected by prostate cancer is recommended by NICE (2019). Robb and Davis (2015) also argued that the medical model was a barrier not only for the provision, but the development of cancer rehabilitation.

However, the medical model not only impacted on the wider MDT, but how the cancer rehabilitation services were provided. Professional boundaries and lack of competency sharing were identified in this thesis, as mechanisms leading to insufficient staff capacity. One of the contexts influencing professional boundaries was the historic service organisation leading to different AHPs pushing their own agenda. This contradicts the biopsychosocial model, as AHPs did not look at the person affected by cancer as whole for

whom the best health and quality of life outcomes could be achieved by the team working together, rather than professionals focusing on particular specialties in isolation.

Moreover, another sign that the biopsychosocial model was not fully in effect regarding the cancer rehabilitation services is the insufficient needs assessment and care coordination. The Cancer Delivery Plan (CDP) and the NICE guidance states that written holistic needs assessment should be provided for every person affected by cancer (Welsh Government 2016a, NICE 2004). However, out of the two cancer rehabilitation services, only the Willow Therapy Team conducted formal written needs assessment at the time of data collection for this PhD study. Due to the lack of formal needs assessment in the Fern Therapy Team, it is possible that certain needs of the person affected by cancer was missed. While the Willow Therapy Team had a formal written assessment, it was adapted to make it shorter, thus, omitting certain elements from the original tool (Macmillan Cancer Support 2018). This could potentially lead to missing physical, psychological, or social needs.

Regarding needs assessment, the Willow Therapy Team also collected outcome measures to screen people's quality of life, fatigue, pain, breathlessness, to examine functional mobility, and to prove the benefits of their services. The team chose outcome measures based on their feasibility in practice. One of these measures was a quality of life scale. However, to understand what this quality of life scale measures, it is important to know how quality of life is conceptualised. WHO (2012) defines quality of life as a person's subjective perception of their place in life considering their goals, standards, and concerns which are influenced by cultural contexts and value systems. This is an overall, all-encompassing definition. However, several different quality of life definitions are available ranging from objective to subjective, from single domain or function oriented to global (Post 2014). Moreover, there is a difference between overall quality of life and health related quality of life (Post 2014).

Health-related quality of life is often considered a subset of overall quality of life, as it only focuses on the domain of health (Torrance 1987). Tate et al. (2002) criticised the concept of health-related quality of life as they believed it aligns with the biomedical model, instead of focusing of different aspects of health and disease. To help people express their own perspectives on health-related quality of life, the concept of subjective quality of life was developed. The quality of life scale chosen by the Willow Therapy Team, while a subjective measure allowing people to express their experiences from their perspective, it mainly

focuses on health. People's response to this quality of life scale might depend on what they understand on best and worst possible health. Based on some people's values this might only mean physical health, while for others this might include psychological health and social issues as well. Thus, it is possible that this measure might not capture all aspects of the biopsychosocial model, potentially perpetuating the medical model. To support the move towards the biopsychosocial model, healthcare professionals might need to consider the use of screening tools and outcome measures that could capture all aspects of health, including physical, psychological, and social to enable truly holistic cancer rehabilitation.

Moreover, throughout this thesis, improved quality of life is mentioned without a distinction between health-related and overall quality of life. In this thesis, quality of life refers mainly to health-related quality of life, as it relies on the outcome measures used by the Willow Therapy Team. However, during the interviews I aimed to capture all aspects of health, including psychological and social domains as well, thus ensuring that a more biopsychosocial model centric view was taken regarding the outcomes of cancer rehabilitation.

#### 11.1.5 Uptake differences in cancer diagnoses and gender compared to the WCPES

As seen in chapter 8, section 8.1.1, there were differences in the yearly uptake of people affected by different cancer diagnoses at the Willow Therapy Team. People affected by breast cancer had the largest representation in the exercises classes which reflects the wider literature. Breast cancer historically is well-represented in the cancer rehabilitation and supportive care literature (Scott et al. 2013, Silver et al. 2017), which could influence referrals to cancer rehabilitation services, as it is more likely healthcare professionals will know about services provided for people affected by breast cancer, thus more likely to advise people to access these services.

Moreover, the literature reviews presented in chapter 3 supports, that breast cancer seems to be one of the most well represented cancer sites in cancer rehabilitation and cancer rehabilitation research. In the overview of qualitative research reviews out of the nine qualitative reviews, four belonged to research investigating the barriers and facilitators of exercise-based cancer rehabilitation for people affected by breast cancer. The rest of the review papers focused on lung cancer ( $n=1$ ), prostate cancer ( $n=2$ ), and people with a wide range of diagnoses, including breast cancer. Moreover, majority of the papers identified for

the qualitative synthesis from healthcare professionals' perspectives focused on people affected by breast cancer ( $n=5$ ).

The Welsh Cancer Patient Experience Survey (WCPES) seem to support that people with breast cancer might receive more practical support than other participants, such as support from the Willow Therapy Team (Welsh Government 2017). Breast cancer was one of the diagnoses with which most people reported to receive practical support with their cancer treatment related side effects (63.4%,  $n=1449$ ) on a national level (Welsh Government 2017). Moreover, when breaking down the WCPES responses into regions, in the University Health Board of the Willow Therapy Team, practical support provision (65%,  $n=257$ ) was higher than the national percentage. This supports the findings of the secondary analysis in this PhD study that people affected by breast cancer were more likely to access cancer rehabilitation interventions of the Willow Therapy Team and receive support.

Other cancer sites, which had lower uptake at the Willow Therapy Team received less practical support and advice with their cancer treatment related side effects than the national percentage (Welsh Government 2017). These responses support that uptake might be an issue in certain cancer groups which supports the findings of this PhD study.

In this PhD study the uptake of people with prostate cancer was less than half of the uptake of people affected by breast cancer over the four-year period the data was analysed. The WCPES responses of people affected by prostate cancer show that higher percentage of respondents did not receive any practical advice or support with their cancer treatment related side effects (20.3%,  $n=128$ ) compared to the national responses (16.4%,  $n=807$ ) (Welsh Government, 2017). These WCPES results could reflect the uptake issues of the Willow Therapy Team regarding people affected by prostate cancer. However, lower percentage of respondents with prostate cancer received limited support (20.3%,  $n=128$ ) than the national average (25.9%,  $n=807$ ). In addition, higher percentage of respondents with prostate cancer (59.4%,  $n=128$ ) received full practical advice and support for their cancer treatment related side effects in the University Health Board than the national percentage (57.7%,  $n=807$ ) (Welsh government, 2017). This indicates that more people with prostate cancer received sufficient support with their cancer treatment related side effects where the Willow Therapy Team resided.

Regarding timelines, the WCPES was conducted in 2016 which followed a sharp increase in the uptake of people affected by prostate cancer at Willow Therapy Team. It is possible that the better regional WCPES results for prostate cancer reflect this new influx into the Willow Therapy Team. However, it could happen that people affected by prostate cancer received practical support from other sources. The University Health Board where the Willow Therapy Team resides covers a sizeable geographical area, with numerous hospitals. It could be possible that people with prostate cancer received support from another hospital. Moreover, specific peer support groups run by a third sector organisation provide support for people affected by prostate cancer including information on managing side effects. As the question in WCPES regarding practical support and information did not specify that support must be received from a hospital, it is possible that people considered help and support from other sources when answering the questions.

However, regardless of why the regional WCPES results were better than the national for people affected by prostate cancer, people with breast cancer still received more support which supports the findings of this PhD study. Moreover, in this PhD study, differences were identified between the uptake of male and female participants. More female participants attended the exercise classes of the Willow Therapy Team than male, which could explain the differences between the uptake of people with prostate and breast cancer diagnoses. In the literature, Handberg et al. (2018) found that men were less likely to access cancer rehabilitation than women due to healthcare professionals' perception of masculinity and gender. Healthcare professionals perceived that men either would not have attended the cancer rehabilitation services or that male participants did not have rehabilitation needs, even though they did have. Although this PhD study did not find specific reasons for the gender differences in uptake, it might be possible that healthcare professionals' perception of gender and masculinity influences information provision about cancer rehabilitation services. Future research could investigate if gender perception influences information provision on cancer rehabilitation in Wales.

## 11.2 Reflections

Reflection is an important part of research as it enhances the rigour of qualitative research (Lincoln and Guba 1985, Korstjens and Moser 2018). Moreover, in a PhD, reflection serves another purpose which is to help the more in-depth understanding of my experiences and help my personal and professional development (Callary et al. 2012). In the following

sections I reflect on the different phases of this PhD study, such as the secondary analysis of routinely collected data, recruitment of participants, qualitative interviews and data analysis.

### 11.2.1 Secondary analysis and the use of routinely collected data

Secondary analysis of routinely collected data can be a rich source of information on how healthcare interventions and services work in the real world (Moen et al. 2017). Moreover, using data that was collected in the real world, in an open system rather than in controlled study, perfectly fit the realist evaluation methodological framework that guided my PhD study. However, dealing with data that was collected by others have its challenges, firstly, acquiring the data.

#### 11.2.1.1 *Acquiring routinely collected data*

Before I could start any work on the routinely collected data, I had to obtain ethical approval. This required gaining permission from the Willow Therapy Team who collected and owned the data, then from the information governance of the University Health Board in which the Willow Therapy Team was located. Gaining permission from the Willow Therapy Team was not an issue. However, liaising with information governance was rather challenging. One of the issues was that my gatekeeper from the Willow Therapy Team was communicating directly with information governance and I only had an indirect role in telling my gatekeeper what to ask and write to the questions of information governance. The second issue was the information governance's lack of understanding on what data was required and what level of permission was needed. The third issue was the slow responses from information governance.

First, having my gatekeeper to communicate with information governance was necessary, as she was responsible for the data, and she had to give permission for my access first. However, not having direct contact with information governance was a potential issue that slowed communication down, as if information governance had any questions regarding what data I was interested in, I always had to wait for my gatekeeper to read her e-mails. However, with the experience I gained over the years, now I would ask my gatekeeper to let me discuss further details with information governance following initial introductions. This could have sped up the process. However, when I started this PhD journey, I was less confident and did not feel like an authority to have requests, such as contacting

information governance directly. Information governance and my gatekeepers felt like an authority to me which, as a novice researcher who just started her PhD study, I did not want to question unless necessary. However, I have grown as a researcher over the years, and now I would happily navigate governance officers and my gatekeepers.

The second issue was the level of access needed. The database contained potentially identifiable data, such as the outward code of a postcodes. I was initially interested in this data, as outward codes could have told us which area people affected by cancer travelled from to attend the exercise classes of the Willow Therapy Team. This would have been a particularly interesting data, as the qualitative interview findings show that travelling can be a challenge for people to attend cancer rehabilitation services. However, information governance insisted that to access this data retrospective consent would have been needed from people affected by cancer. However, the database contained information from people who had died. Therefore, asking permission to use their data might have not been possible, or would have been inappropriate to bother the family with such requests. This could have influenced the sample size and the investigation of service uptake numbers. Moreover, there was a possibility that people who are alive and could be contacted would not respond to a request for retrospective consent. Therefore, I had to make the decision to access the non-identifiable data only.

Information governance gave permission to access the non-identifiable data, so I could start the ethical approval application process. With more research experience now, I think making the decision not to go down a retrospective consent road, was the right compromise. Having access to the full dataset highlighted uptake fluctuations over the years, differences in the number of people with different cancer diagnosis and gender. Moreover, having the full dataset helped the identification of issues with how the data was collected, the variations in the sample sizes of different outcome measures, and the missing data. Having this information enabled me to have a critical view on my findings and to give recommendations for future clinical practice, such as the importance of establishing a shared agreement on how data is collected by a team to avoid unwanted variability in data collection and ensure that cancer rehabilitation services have high quality data to rely on when promoting their work and applying for grants.

The third issue with acquiring the data was the slow response from information governance. This delayed my study in the beginning quite considerably. However, leading



back to the first point of being able to directly contact information governance might have helped me receive answers regarding access to identifiable and non-identifiable data quicker, speeding up the process of gaining permission. My initial lack of confidence as a novice researcher hindered my ability to take control of certain situations. However, throughout this PhD journey I have gained confidence and would be more assertive in trying to get a response. In addition to challenges with acquiring data, managing the data itself was at times difficult. In the next section I reflect on how I managed the database.

#### *11.2.1.2 Managing routinely collected data*

Using routinely collected data from a secondary source has its challenges. In this PhD, high amount of missing data, variability in reporting, and the modification of validated questionnaires was an issue that I needed to manage. As mentioned above in chapter 7, the reasons for the high amount of missing data were disengagement from the cancer rehabilitation services before their follow-up assessment, and healthcare professionals leaving outcome measures out based on their professional judgement. If I collected the data, I could have made steps to avoid missing data or to mitigate as much as possible. However, as this routinely collected data was from a secondary source, I felt helpless. I had several meetings with the team prior to gaining ethical approval and access to the database to learn what data they collected and how. However, it could not prepare me to the challenges that I needed to face. To try and handle the missing data I dig myself deep into data science. However, as the amount of missing data was too high, no measures, such as multiple imputation technique, could be used to try and replace or make up for the missing values. Therefore, in the end I decided to use the methods of Jakobsen et al. (2017), and apply complete case analysis, and provide a detailed description on how and why the data was missing. Although figuring out how to deal with the missing data was a stressful process, I learnt a lot about data science which will be useful in my future research carrier.

In addition to the variability in data collection between healthcare professionals based on their judgement, the reporting of episode 0 was another discrepancy. As mentioned in chapter 9 (section 9.5), using episode 0 might have been a habit of a certain professional, as following a sharp drop in episode 0 cases in 2016, episode 0 was never reported again. This coincides with a healthcare professional leaving the Willow Therapy Team, supporting this claim. Although, initially I did not know how to handle episode 0, I decided to leave these cases in as they reflected issues with how the therapy team collected data, pointing to

issues with the consistency of data collection between different team members, contributing to my findings in this PhD thesis. This helped me learn that issues with the data can be a study finding. This coupled with the qualitative interview findings implying that healthcare professionals lacked the strategic insight into why data was necessary to collect. These findings helped the development of an alternative CMO\_3, indicating that there is a vicious cycle between healthcare professionals time, data collection, and staff capacity.

Moreover, when receiving routinely collected data following ethical approval, I noticed that one of the outcome measure results I initially planned to use seemed incorrectly input. The Willow Therapy Team collected EuroQol 5 Dimensions 5 Level version (EQ5D-5L) which is a widely used generic quality of life questionnaire (Herdman et al. 2011). The questionnaire looks at five domains of health, for example, mobility, pain, and self-care. The five domains each are scored from 1 to 5 and usually presented separately, as they are used to calculate weighted utility index scores (Herdman et al. 2011). However, the team made the individual scores into a summary score. In addition, as they used the EQ5D-5L with FACIT-F, they adapted the scoring from the fatigue measure, which ranges from 0 to 4, thus rendering the EQ5D-5L data unusable for analysis.

Although the Willow Therapy Team collected data with the best intentions, their understanding of the use of a validated questionnaire led to quality issues with the data. This data issue was surprising for me and a little daunting as a novice researcher. However, it taught me early on that research does not always work as initially planned. Resilience and learning from mistakes are part of the research journey.

After discovering the issues with the EQ5D-5L data, I discussed this with the supervisory team and the Steering group. As members of the Willow Therapy Team were part of the Steering Group, this provided an opportunity for feedback on practice. After I let the representative Willow Therapy Team member know of the data issues, the Willow Therapy Team changed how they collected data and started scoring EQ5D the right way.

Moreover, as mentioned in chapter 10 (section 10.3.1) the Willow Therapy Team also modified the concerns checklist (Macmillan Cancer Support 2018) designed to assess the needs of people affected by cancer. This change might have led to insufficient needs assessment. Thus, this issue also highlights that healthcare professionals need to have a better understanding of how data should be collected. Although initially I thought of this as

a weakness of this PhD study, throughout conducting my PhD I realised that this could be a finding and a valuable feedback to the Willow Therapy Team.

### 11.2.2 Recruitment for qualitative interviews

As seen in chapter 7 (section 7.1.2), the response rate of people affected by cancer to take part in this study was low, particularly for the Fern Therapy Team. I indirectly recruited people affected by cancer, meaning that the healthcare professionals with whom people had an already established relationship with were inviting people to the study. People then were able to contact me with a response slip that was given to them with a pre-paid envelop. Moreover, I provided my contact telephone number and my e-mail address in the invitation letter, so people could contact me directly without sending the response slip back. This way I tried to ensure that people's participation stays anonymous from the two Therapy Teams. However, my indirect involvement in the recruitment could have led to people not wanting to sign up for a study that had a researcher unfamiliar to them.

Moreover, I could not control how the invitation letters were handed out, which could have led to healthcare professionals not giving these out at the right time for the person affected by cancer. Although I met the two Therapy Teams several times and made a presentation on how invitation letters should be handed out, it is possible that in reality recruitment was not conducted as discussed. In future research, I need to consider different recruitment strategies, or the use of social media in inviting people for research studies.

Moreover, another possible explanation to the low response rate is that the Fern Therapy Team mainly sees people affected by cancer in an acute setting, throughout their treatments. My findings show that people often consider cancer rehabilitation as aftercare; therefore, they might have not signed up for the study during active treatment as they could have thought that they had not reached the rehabilitation phase.

Moreover, response to a study inviting people for cancer rehabilitation research could depend on the intervention people received. For example, Participant\_21 received acupuncture, although she indicated that she thought of acupuncture as maintenance, rather than rehabilitation. While Participant\_21 still signed up for this PhD study, others who did not consider the interventions that they received from the therapy team as rehabilitation might have not signed up. In the future, in a possible continuation to this

study, I need to consider the language used for recruitment, and instead of rehabilitation maybe the word support, or help with side effects could be used.

### 11.2.3 Reflections of the qualitative interviews

Reflection in qualitative research is an important part of rigour (Lincoln and Guba 1985). Therefore, this section aims to explore my experiences with qualitative research and how I could have potentially influenced the research findings.

I have always been drawn to capturing people's experiences in the form of interviews. Therefore, I was excited to conduct my first qualitative research. As a first time, novice qualitative researcher, I was nervous as I tried to capture the lived experiences of people affected by cancer in a rigorous way, while I tried to use elements of realist interviewing techniques to test my initial programme theories (IPTs). This initially resulted in me asking questions in ways that I might have seemed to lack confidence. This often led to asking too long questions, pausing a lot in mid question or forgetting questions. However, by the time I conducted the last interview I gained a lot of confidence and the way I asked questions became easier.

Moreover, I have been conducting this research in a second language, as originally, I am from Hungary, and my mother tongue is Hungarian, which could have added to my confidence issues. However, I have received feedback from a few healthcare professionals that the interview was friendly, and they felt like we had a good conversation instead of an interview. This might have helped healthcare professionals to open up to me and disclose more about the potential contexts that could inhibit the provision of cancer rehabilitation.

Moreover, some people affected by cancer indicated that the interview that they had with me was therapeutic. Therefore, what I considered as a lack of confidence initially, it might have helped me become more relatable for healthcare professionals and people affected by cancer. The length of interviews might support this, as some interviews both with healthcare professionals and people affected by cancer lasted over an hour, up to 90 minutes.

Regarding the qualitative data analysis, similar to conducting interviews, this was my first time using qualitative data analysis. I chose thematic analysis by Braun and Clarke (2006) as it is often recommended for novice researchers. However, as I was conducting a realist

evaluation, I had to apply retroductive thinking to my analysis. Trying to identify possible mechanism, and contexts that influenced them was a hard, time-consuming, and often difficult process. Sometimes I even coded the data too meticulously, with often coming up with 192 codes for one interview.

I also wanted to make sure that I properly represent the views of people affected by cancer, which was an added level of pressure. Due to my meticulous coding, it is possible I created codes and themes, that otherwise I would not have been able to do. However, this also affected my time-management and led to missed deadlines. As a researcher I needed to learn to manage time and data wisely. There is no such thing as perfect research, thus pragmatic approaches to data analysis should be a priority.

To keep my data analysis manageable, I used the rough topic of each IPT, which I presented in a Microsoft Excel sheet to make visualisation easier. I started inputting codes according to which IPT they roughly related to. However, this meant that codes not relating to information provision, staff training, or individualised tailored care had to be left out. Punton et al. (2020) suggest the use of IPTs to limit the findings and keep data analysis manageable. Moreover, scientific realism holds that knowledge gained from research will always be partial, thus researchers need to accept the limitation of realist research. While I aimed to focus on the IPTs built, certain themes, that were important to how information provision, healthcare professionals' training, and individualised cancer rehabilitation worked, were added creating new alternative CMOs.

Codes and themes that did not relate to either the alternative CMOs or the original IPTs had to be left out. These topics included general cancer treatment experiences of people affected by cancer, and downward comparison (people compared themselves to others who seemed in worse condition, considered that they could have had it worse). To explore people's and healthcare professionals' experiences in-depth and use the data left out of this realist-informed evaluation, I plan to conduct a secondary analysis of the qualitative interview data.

### 11.3 Strength and limitations

In this section following the reflections, I consider the strength and limitations of this PhD study.

### 11.3.1 Strengths

- Realist evaluation methodological framework guided this PhD study, providing rich, detailed CMO configurations that helped identify service provision issues with two cancer rehabilitation services in South Wales.
- I have transcribed every single interview, while taking extensive notes of my initial thoughts on the data. This helped me familiarise myself with the data and aided analysis of the findings.
- The principles of trustworthiness in qualitative research were used throughout this PhD study. Methodological triangulation, clear audit trail, thick descriptions, reflective diary, and consultations with the supervisory team ensured the rigour of the qualitative analysis.
- Although, the secondary analysis had its challenges, providing a detailed analysis plan and consideration for the missing data is the strength of this thesis.

### 11.3.2 Limitations

- The database used for the secondary analysis contained a high percentage of missing data. Dixon's (1992) method and chi square tests conducted to determine the pattern of missingness indicate that data was not missing completely at random (MCAR). Interview extracts show that one of the reasons behind missing data was that healthcare professionals did not report outcome measures that they thought was not appropriate for the person affected by cancer. Moreover, chi square test indicates that disengagement from the services of the Willow Therapy Team was another possible reason for missing data. The reason for disengagement is not known. However, this could potentially influence the findings. Therefore, when interpreting the findings of the secondary analysis it is important to note that while quality of life and functional outcomes improved post rehabilitation, these findings only apply to a portion of the population, and the sample might not be representative of the wider cancer population.
- Majority of people affected by cancer interviewed for this PhD study were proactive in their efforts to find services that could help with their cancer treatment related side effects and health needs. Moreover, a high proportion of the participants had a physically active lifestyle prior to their cancer diagnosis. Therefore, they might not be fully representative of the whole cancer population.

- The sample size for the qualitative interviews was low. This was particularly an issue from the perspective of the Fern Therapy Team as people affected by cancer had different interventions, including fatigue management, acupuncture, SLT and dietitian input.
- No ethnic minorities signed up for this PhD study. Therefore, findings might not represent their perspective on cancer rehabilitation.

## 11.4 Implications for clinical practice

The findings of this PhD study highlighted issues with information provision on cancer rehabilitation and treatment related side effects, training of non-specialist healthcare professionals, professional boundaries, and cancer rehabilitation services provision. To help provide high quality cancer rehabilitation for every people affected by cancer who need it I would like to make the following recommendations for practice.

- Therapeutic relationships need to be managed to enable people affected by cancer to self-manage. Boundaries to cancer rehabilitation services need to be set with clear, focused, and achievable rehabilitation goals.
- Group based psychosocial interventions, such as the fatigue management organised by the Fern Therapy Team would benefit from a more mixed group of participants to enable age-matched peer support. To achieve bigger groups, increased service promotion might be required.
- Regarding the exercise classes provided by the Willow Therapy Team, session timings need to be more flexible to cater for a wider population of people affected by cancer. In its current form, sessions are not available for younger people who might work full time, limiting access to cancer rehabilitation.
- A framework or model that could actively help manage professional boundaries and sharing competencies is needed.
- Care coordination needs to be better managed to help reduce the health needs of people affected by cancer. There needs to be a consensus among healthcare professionals on whose responsibility is to conduct needs assessment and signpost to appropriate cancer rehabilitation or support services.
- Healthcare professionals' time and staff capacity has an impact on the provision of cancer rehabilitation. As healthcare professionals reported, time was a major context that influenced data collection which could have helped them to show the

impact of cancer rehabilitation, promote services and gain funding. However, without sufficient number of staff, healthcare professionals were unable to collect data keeping them in a vicious cycle. The findings of this PhD study could help make a case for increasing staff capacity to enable healthcare professionals' efforts to collect data and promote services.

- Healthcare professionals need to make sure that if they collect data, all team members need to agree on a consistent, systematic way of data reporting. The Transforming Cancer Services Team (2017a) has been working on the minimum required data that healthcare professionals working in cancer rehabilitation should collect.
- Cancer rehabilitation services need to be promoted and education for the wider MDT and non-specialist colleagues need to be provided. Knowledge of the wider MDT on cancer rehabilitation needs to be increased to improve referral rates to cancer rehabilitation services. Moreover, non-specialist healthcare professionals need to receive a basic level awareness training on cancer rehabilitation to give them the knowledge and confidence to see people affected by cancer who only gave generic health needs, such as basic dietary advice, or simple exercises.

## 11.5 Recommendations for future research

- As mentioned in section 11.1.2, future research could focus on connection between autonomy, competence, patient activation, and people's education level.
- Longitudinal studies could be conducted to see if self-management behaviours are maintained following discharge from the cancer rehabilitation services.
- In this PhD study people affected by cancer who attended the services of either the Willow or Fern Therapy Teams were interviewed. However, interviewing people, who did not receive any cancer rehabilitation interventions from these Teams, could increase the knowledge base on what influences cancer rehabilitation service uptake.
- As mentioned above, in section 11.1.5, questions in the WCPES might not be specific enough, as it does not specify if people received practical support from a local hospital or from a third sector organisation. Moreover, practical support is a broad term that can include many interventions. Therefore, potentially a cancer



rehabilitation specific experience survey could be developed to assess if people received help with their cancer treatment related side effects.

- As noted in section 11.1.5, the database of the Willow Therapy Team indicates potential gender differences in uptake. It was out of the scope of this PhD study to investigate the reason for gender differences. However, future research could potentially focus on gender differences in accessing cancer rehabilitation.
- This PhD study focused on the experiences of oncology specialist AHPs. These AHPs identified issues with the knowledge and confidence of their non-specialist colleagues and the knowledge of the wider MDT. In the future investigating the experiences of non-specialists and the wider MDT could help identify new CMO configurations.

## 11.6 Impact of the COVID-19 pandemic on cancer rehabilitation services

The COVID-19 pandemic brought unwanted changes into all our lives. Its severe impact left a mark on everything, including the cancer services (Lai et al. 2020). The Fern Therapy Team had to stop all outpatient services and the dietetic drop-in clinic to stop the spread of COVID-19 last March. No services have been restarted as the cancer centre where the Fern Therapy Team is located in have severe restrictions.

Regarding the Willow Therapy Team, similar to the situation of the Fern Therapy Team, the exercise classes were stopped in March 2020. Many staff members were redeployed, although they have been struggling with staff and funding before the pandemic started. Last November they mentioned that they could have potentially reopened if they conducted a risk assessment. However, due to lack of staff, the Willow Therapy Team was unable to provide a risk assessment and reopen.

## 11.7 Conclusion

Cancer treatment related side effects can have a long lasting impact on people's lives (Macmillan Cancer Support 2015). Cancer rehabilitation interventions have been found to improve quality of life and help people manage treatment related side effects (Hunter et al. 2017a,b, Peddle-McIntyre et al. 2019). For the purposes of this thesis cancer rehabilitation was defined as a complex set of interventions aiming to enable people affected by cancer

and their families to achieve maximal physical, psychological, emotional, social, and economic functioning within the limits of the disease, from diagnosis until the end of life. However, the WCPES indicated that 41.3% of respondents (n=5994) who need practical advice and support (advice on exercise, diet, or symptom management) received no (14.5%) or limited care (26.8%) (Welsh Government 2017). However, the reason for this lack of support has not been known. The aim of this PhD study was to investigate what works in two cancer rehabilitation service in South Wales, for whom, in what circumstances, and how.

Realist evaluation methodological framework guided the conduct of this PhD study. Initially, IPTs were developed based on policy, the wider literature and input from a Steering group of experts who worked in the field of cancer rehabilitation. Then, the IPTs were tested with a mixed methods investigation, which included the secondary analysis of routinely collected data and qualitative interviews from the perspectives of people affected by cancer and healthcare professionals.

As a result of testing the initial programme theories three main CMO configurations were developed with four additional alternatives. The findings indicate issues with information provision to increase people's knowledge on available cancer rehabilitation services and on treatment related side effects. Information provision was influenced by several contexts including lack of consensus on what cancer rehabilitation means, wider MDT's perception, and knowledge on cancer rehabilitation, the prevailing medical model in healthcare, among others. Due to these context people received insufficient information leading to fluctuation in the uptake of cancer rehabilitation services and uncertainty and stress caused by the lack of knowledge on cancer treatment related side effects.

Healthcare professionals reported issues with training and professional boundaries that due to the non-use of the four level model led to an insufficient range and volume of both specialist and non-specialist cancer rehabilitation services and staff capacity. Moreover, historical service organisation that forced healthcare professionals to push their own agenda deepened professional boundaries, while healthcare professionals lack of time often contributed to issues with receiving training. In addition to issues with training and professional boundaries, the findings indicate that healthcare professionals are often trapped in a vicious cycle of time and staff issues. Lack of time led to professionals not

being able to collect data, or do service promotion activities, leading to lack of funding and lack of staff which further enhanced time issues.

The last CMO focused on individualised, tailored cancer rehabilitation interventions, which led to improved quality of life and reduced health needs if the context was supportive with well managed therapeutic relationships, family and peer support. However, insufficient needs assessment, not managed therapeutic relationships, unmatched peer support, and inaccessibility of services could lead to unmet health needs and people's lack of self-management.

These findings indicate that issues exist in the provision of cancer rehabilitation in South Wales, which need to be addressed to help people manage their cancer treatment related side effects.

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## Appendices

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### Appendix 1: Cancer rehabilitation definitions chart (continued on the following pages)

Author	Paper	Paper type	Year	Location	Definition
Dietz, J. H.	Rehabilitation of the Cancer Patient: Its Role in the Scheme of Comprehensive Care	Seminal work	1974	USA	“Readaptation is the synonym for rehabilitation and is defined as accommodation or adjustment to personal needs for survival - physical, psychological, financial and vocational. Emotional adjustment is, of course inherent in the psychological adjustment. Such readaptation, to be successful, must ensure an appropriate and attainable goal for each patient.”

Author	Paper	Paper type	Year	Location	Definition
Fried, D.	Rehabilitation of the Cancer Patient	Congress paper	1975	USA	“First we should define rehabilitation in simple terms. Rehabilitation is restoration. I think of it as maximal restoration. This obviously implies that 100% restoration is not always achieved, but we try to restore the patient as much as we can. This includes not only physical but also economic restoration. Can the patient go back to work and earn a living? We also think of rehabilitation in a social sense. Is the patient able to live again in the same family situation and in the same community? Psychological rehabilitation is also mandatory.”
Cromes, G. F.	Implementation of Interdisciplinary Cancer Rehabilitation	Seminal work	1978	USA	“Cancer rehabilitation involves helping a person with cancer to help himself or herself to attain maximum physical, social, psychological, and vocational functioning within the limits imposed by the disease and its treatment. Especially important in this definition are the ideas of self-help strategies and goal planning that include attention to quality of life.”
Dudas, S.	Rehabilitation concepts of nursing	Review	1984	USA	“Rehabilitation is a dynamic process directed towards the goal of enabling persons to function at their maximum level within the limitations of their disease or disability in terms of their physical, mental, emotional, social, and economic potential.”



Author	Paper	Paper type	Year	Location	Definition
Gunn, A. E.	Cancer rehabilitation.	Book	1984	USA	“Rehabilitation, broadly conceived, is the restoration of a patient with residual deficits as a result of his disease, or its treatment, to as normal a functional state as possible.”
Mayer, D. and O'Connor, L.	Rehabilitation of persons with cancer: an ONS position statement.	Position statement	1989	USA	“Rehabilitation is a process by which individuals, within their environments, are assisted to achieve optimal functioning within the limits imposed by cancer.”
Watson, P.G.	Cancer rehabilitation: The evolution of a concept	Review	1990	USA	“Cancer rehabilitation is a dynamic, health-oriented process designed to promote maximum levels of functioning in individuals with cancer-related health problems.”
McKenna, R., Wellisch, D., and Fawzy, F.	Rehabilitation and supportive care of the cancer patient	Book chapter	1995	USA	“In the broadest sense, the goal of cancer rehabilitation is to enable patients to achieve as normal and full a life as possible.”

Author	Paper	Paper type	Year	Location	Definition
Barg, F.	Rehabilitation	Book chapter	1997	USA	“Rehabilitation is a dynamic, ongoing process intended to maximise an individual's capabilities within the limitations of the disease or disability.”
Veach, T., Nicholas, D. and Barton, M.	Cancer and the family life cycle: a practitioner's guide.	Book	2002	USA	“Rehabilitation is the process by which patients and families are helped to recover their functional status while maintaining a high quality of life.”
The Nordic Cancer Union	From Needs to Offers – Rehabilitation of cancer patients	Report	2004	Nordic Countries	“Cancer rehabilitation is a specific period of time during which the physical, psychological, social and existential consequences of cancer and the treatment are prevented and reduced. The rehabilitation initiatives are to have clear objectives and effects, and provide each individual patient help and inspiration to have the best possible life. The individual rehabilitation plan is to be prepared in a close dialogue between the patient and the professionals.”

Author	Paper	Paper type	Year	Location	Definition
National Institute for Health and Care Excellence (NICE)	Improving Supportive and Palliative Care for Adults with Cancer	Guideline	2004	UK	“Cancer rehabilitation attempts to maximise patients’ ability to function, to promote their independence and to help them to adapt to their condition. It offers a major route to improving their quality of life, no matter how long or short the timescale. It aims to maximise dignity and reduce the extent to which cancer interferes with an individual’s physical, psychosocial and economic functioning.”

Author	Paper	Paper type	Year	Location	Definition
Wells, M. and MacBride, S.	Rehabilitation and survivorship	Book chapter	2006	UK	“It seems that the key to rehabilitation must be to understand who the person was prior to diagnosis, how and why things have changed as a result of having cancer and where the person would like to be. Within this context, it is possible to set goals that are both realistic and patient-centred. In 1984, Kenneth Calman hypothesized that quality of life in cancer patients represents the difference between the hopes and expectations of the individual and the actual experience of their present situation. Perhaps it is the role of rehabilitation to lessen the gap between these two realities.”
Cheville, A., Khemka, V., O' and Mahory, S.	The Role of Cancer Rehabilitation in the Maintenance of Functional Integrity and Quality of Life	Book chapter	2007	USA	“The purpose of rehabilitation as outlined in this chapter is to improve the quality of life irrespective of etiology or anticipated survival.”

Author	Paper	Paper type	Year	Location	Definition
Gamble, G. L. et al.	The Future of Cancer Rehabilitation	Invited review	2011	USA	“Cancer rehabilitation, by definition, is a broad spectrum specialty, encompassing the treatment of symptoms and functional impairments from very young patients through all stages of adulthood and through many phases of disease and disability throughout the trajectory.”
Silver, J. K. et al.	Cancer rehabilitation and palliative care: critical components in the delivery of high-quality oncology services	Review	2015	USA	“Cancer rehabilitation is medical care that should be integrated throughout the oncology care continuum and delivered by trained rehabilitation professionals who have it within their scope of practice to diagnose and treat patients’ physical, psychological and cognitive impairments in an effort to maintain or restore function, reduce symptom burden, maximize independence and improve quality of life in this medically complex population.”

Author	Paper	Paper type	Year	Location	Definition
Eckerdal, G.	National care program for cancer rehabilitation [Nationellt vardprogram Cancerrehabilitering].	Report	2017	Sweden	"Cancer rehabilitation services aim at preventing and reducing the physical, psychological, social, and existential consequences of a cancer diagnosis and its treatment. The rehabilitation services shall give the patient and next of kin support and help to achieve as good a life as possible." "Cancer rehabilitation aims to prevent and reduce the physical, mental, social and existential consequences of cancer and its treatment. The rehabilitation efforts should provide patients and related support and the conditions for living as good a life as possible "

Appendix 2: Data extraction table for overview of reviews (continued on the following pages)

Author	Year	Location	Sample	Method	Risk of bias	Themes
Browall et al.	2018	Sweden	17 qualitative papers; people affected by breast cancer during and after treatment	Integrative review; PRISMA guidance followed; Thematic synthesis based on Thomas and Harden; CASP used for quality assessment	Included studies have a quality between 30% and 90%.	1. <b>Benefits From PA During Treatment:</b> Feelings of Empowerment, Improving Experiences of Health; 2. <b>Benefits From PA After Treatment:</b> Social Support Through Engaging in PA; 3. <b>Facilitators for participating in PA:</b> Support with Recovery and Prevention, Skilled Instructors, Company with Peers; 4. <b>Barrier to participating in PA:</b> Social factors, Health-related and physical factors, Lack of information
Clifford et al.	2018	Australia	10 qualitative (n=3 mixed; n=1 colorectal; n=3 breast; n=3 prostate) and 9 quantitative	PROSPERO registered; Mixed methods systematic review; Mixed Methods Appraisal Tool (MMAT-Version 11) used for quality assessment; Thematic synthesis based on Thomas and Harden	Studies excluded under the score of 75% MMAT.	Barriers and facilitators of exercise (treatment-related side effects; lack of time; fatigue); Exercise preferences

Author	Year	Location	Sample	Method	Risk of bias	Themes
Fox et al.	2019	UK	15 qualitative and 17 quantitative; people affected by prostate cancer with any treatment status	PROSPERO registered; Mixed methods systematic review; JBI appraisal tools used; Thematic synthesis based on Thomas and Harden.	<b>Quantitative:</b> RCTs - lack of blinding; Cohort studies - lack of transparency on confounding factors; Non-RCT trials - no bias; cross-sectional studies - lack of transparency on confounding factors, lack of objective outcome measures; <b>qualitative research</b> - lack of clarity between philosophical perspective and methodology; lack of reflexivity	Individual needs by treatment pathway; Self-determination and its relationship with prostate cancer-related event; Co-ordination and support of the clinical care team; Individual preferences in discrete aspects of PA engagement style; The potential for bidirectional facilitative relationship between structured group PA and spontaneous peer support
Granger et al.	2017	Australia and UK	11 qualitative, 9 cross-sectional, 4 case series; people affected by lung cancer	PROSPERO registered; Mixed methods systematic review; PRISMA and ENTREQ guidance followed; Thematic synthesis based on Thomas and Harden; Findings were mapped onto COM-B system; Newcastle-Ottawa Quality Assessment Scale (NOS) appraisal tool for case series studies; Agency for Healthcare Research and Quality Methodology Checklist for Cross-Sectional/Prevalence Studies; COREQ for qualitative studies	Overall risk of bias was moderate to high. Quantitative: Case series - lack of comparability, inadequate reporting of recruitment time period; Cross-sectional - handling of missing data; Qualitative studies - lack of reflexivity	1. Patient motivation and beliefs; 2. Patient pre-diagnosis PA habits and perceived relevance; 3. Physical influences; 4. Psychological influences; 5. Social influences; 6. Environmental and structural influences



Author	Year	Location	Sample	Method	Risk of bias	Themes
Lavallée et al.	2019	UK	13 qualitative studies; people affected by breast cancer during adjuvant treatment	PRISMA guidance followed; CASP and Yardley's criteria used for quality assessment; Qualitative metasynthesis; Thematic synthesis based on Thomas and Harden; review findings quality checked based on GRADE-CERQual framework	Relationship between researchers and participants were rarely reported, which influences transparency and coherence. Lack of reflexivity.	Side effects of the treatment; Beliefs about physical activity; Focus on health not illness; Social factors
Livsey and Lewis	2019	UK	6 qualitative studies; people affected by breast cancer and supervised exercise	CASP used for quality assessment; Thematic synthesis based on Thomas and Harden's method	Overall medium quality qualitative papers included: 3 had low quality, 1 had medium quality, 2 had high quality; Bias due to: lack of explanation why the research design was chosen; lack of reflexivity and addressing the relationship between researchers and participants	<p><b>1. Control:</b> Control over cancer and recurrence of cancer; Control over their bodies, health, and fitness; Control over pain and emotions; 2. <b>Focus:</b> Focus on themselves; 2. <b>Transitioning phase:</b> Regaining a sense of normality; Moving forward; Perceived self-identity; 3. <b>Regaining a sense of confidence:</b> Increased self-confidence; 4. <b>Enhanced spirits;</b> 5. <b>Social support:</b> Shared experiences and understanding; Appreciation of the exercise instructor; 6. <b>Safe environment:</b> Feeling safe</p>

Author	Year	Location	Sample	Method	Risk of bias	Themes
Michael et al.	2020	USA	6 qualitative; 8 cross-sectional survey or questionnaire; 2 mixed methods (numbers do not add up in the paper; these are modified numbers); people affected by breast cancer	Mixed methods systematic review; PRISMA guidance followed; CASP used for quality assessment	1. Recall bias: 5 studies; 2. Small sample size: 5 studies; 3. Homogeneity: 5 studies; 4. Others (nature of the study, recruitment, data collection, theme categorisation, single data collection point, role of the researcher)	<b>1. Reported barriers to Physical Activity:</b> Physical Barriers, Psychosocial Barriers, Environmental Barriers, Socioeconomic Barriers; <b>2. Common Patient Perception of Physical Exercise;</b> <b>3. Common Patient Preferences for Physical Exercise;</b> <b>4. Common Motivators for Physical Exercise;</b> <b>5. Recommendations for Adherence to Physical Exercise:</b> Group-Based Programs, Enhancing Self-efficacy, Education on Home-Based programs/alternatives; Experienced Instructors
Midtgaard et al.	2015	Denmark	19 qualitative studies: n=11 mixed; n=1 colorectal; n=1 lung; n=1 prostate; n=4 breast; n=1 rectal	Qualitative synthesis based on Sandelowski and Barroso; CASP used for quality assessment	Quality scores ranged from 6 to 9 (out of 0-9), with a mean of 7.7; indicating generally good quality of research. Main issues were: lack of explanation of recruitment strategy; saturation of data; lack of reflexivity and exploring the relationship between participants and researcher	<b>1. Emergence of continuity:</b> New purpose, goal setting, positive distraction; <b>2. Preservation of normality:</b> Social support, Autonomy, Affirmation of own health; <b>3. Reclaiming the body:</b> Enhanced performance, Safety through professional supervision, Overcoming barriers

Author	Year	Location	Sample	Method	Risk of bias	Themes
Yannitsos et al.	2020	Canada	16 qualitative studies; people affected by prostate cancer; Interventions were: 4 diet alone; 5 both diet and exercise; 7 exercise only	Scoping review following Arksey and O'Malley (2005) framework	No formal quality assessment (this is not requirement for scoping reviews)	<b>Barriers to lifestyle change:</b> Lack of clarity of evidence, Treatment side effects, Perceptions of change as unnecessary, Time pressure, Age; <b>Facilitators to lifestyle change:</b> Healthcare professional involvement, Support, Coping with prostate cancer

Appendix 3: Data extraction table for qualitative synthesis (continued on the following pages)

Author	Year	Location	Intervention	Sample	Method	Themes
Baker et al.	2015	USA	Weight management among long-term cancer survivors (Demark-Wahnefried et al. 2012 considers weight management as part of cancer rehabilitation)	33 participants (prostate, breast and non-Hodgkin lymphoma; 22 academic and 11 community setting) 7 medical oncologists, 3 radiation oncologists, 5 surgeons, 6 primary care physicians, 7 nurses, 5 other (dietitians, social workers and patient navigators)	In-depth, semi-structured interviews (suggested interview guide); Interviewers were PI and research assistant; audio recorded and transcribed; ATLAS.ti 7 used for coding; Constant comparative method (no other method mentioned) no mention on who transcribed the data	Conceptualization of Body Size and Weight Management (Weight and Acute Treatment; Cancer Outcomes Risk; Overall Health); Discussion of Weight Management with survivors (Frequency, timing, and Initiation of Discussions; Framing of Discussions; Diet and Physical Activity Recommendations); Beliefs about survivor's ability to achieve healthy weight (Futility versus success stories; Survivor-Level Barriers and Facilitators; Capacity-Level Barriers and Facilitators)
Beidas et al.	2014	USA	Four small group PT exercise sessions aimed at women with breast cancer and lymphedema (PAL) and home-based strength training twice a week, possibly for 13 weeks	19 healthcare providers (7 physicians, 10 physical therapists (PT), 2 nurse practitioners); 17 direct clinical observations	Semi-structured interviews and direct observations (pre-developed interview guide); group or individual interviews; thematic saturation used for recruitment; detailed field notes used for observations; audio recorded interviews and professional transcription; analysed in NVivo 10.0; modified grounded theory; two researchers coded interviews and notes; constant comparative method used; no mention of interviewer	Intervention characteristics; Payment; Eligibility Criteria; Referral Process; The need for a champion; adaptations

Author	Year	Location	Intervention	Sample	Method	Themes
Bourke et al.	2018	UK	Implementation of 12 week long, supervised, twice a week resistance and aerobic intervention for men (prostate cancer) having androgen deprivation therapy suggested by NICE 2014 CG175	37 healthcare professionals (9 urologist, 10 oncologist, 6 Cancer nurse specialists, 3 GPs, 3 Physio, 2 exercise specialist, 1 service manager, 3 clinical commissioner, 1 primary care physician); 26 men on ADTs; 95 survey responders from 79 NHS trusts out of 154	Semi-structured, face-to-face or phone interviews with healthcare professionals, length about 20-50 min (pre-developed interview guide); focus groups with men on ADT; Electronic survey; digitally recorded interviews transcribed verbatim; NVivo for analysis and thematic framework approach; Double coded by researchers. Two independent investigators rated survey data; COREQ standards	<b>Professional interviews:</b> Impact of ADT: QOL; Embedding in the NHS: Delivery of a supervised exercise training programme, Role of the MDT; Commissioning: Cost-effectiveness; HCP barriers: Traditional values; HCP Training: Behaviour change and communication. <b>Patient focus groups:</b> Experience of hormone therapy: Adverse effects and impact on QOL; Adherence: Barriers, Solutions; Patient centred design: Referral process.
Carter et al.	2014	Canada	Support needs and support provided (pain management, emotional, information and incontinence support...etc.) for men with advanced prostate cancer	19 healthcare providers (12 nurses, 4 physicians, 3 allied health (social worker and care co-ordinator)); only 1 member working in rehabilitation (1 physician)	Qualitative, descriptive methodology by Sandelowski (2000); face-to-face semi-structure interviews (2 focus groups n=5 and 9; 5 individual interviews); transparent-published interview guide; principal investigators interviewing; 40-90 minutes long interviews; audio recorded and transcribed interviews (no mention of transcription); saturation used; member checking used for trustworthiness; analysis journal by researcher; data analysed by a team of 4 members; thematic content analysis by Burnard (1991)	Pain and symptom management; Informational needs; Emotional Support; Practical Assistance

Author	Year	Location	Intervention	Sample	Method	Themes
Dennett et al.	2020	Australia	Exercise-based rehabilitation programs in acute cancer setting	25 professionals (13 nurses, 3 oncologists, 1 haematologist, 8 AHPs); 9 patients (3 breast, 1 ovarian, 1 Non-Hodgkin lymphoma, 3 diffuse large B-cell lymphoma, Acute myeloid leukaemia)	Phenomenological approach; semi-structured interviews (transparent-published interview guide); first article exclusion criteria mentioned; purposive sampling; 45-min interviews; 4 focus groups (3 professional and 1 patient) and individual interviews (10 telephone or in-person); two researchers interviewing; Audio-recorded and verbatim transcription; Three researchers line-by-line coding; open coding in NVivo; Rich description of participants and audit trail for credibility; reflection on researchers; COREQ standards	<b>Main theme:</b> finding the 'right time' for rehabilitation; <b>Sub-themes:</b> Attitudes, Knowledge, Convenience, Resources
Fong et al.	2018	Canada	Promotion and counselling of physical exercise by clinicians for breast cancer survivors	27 professionals (10 oncologists, 2 radiation oncologists, 1 general practitioner in oncology, 2 primary care physicians, 8 registered nurses, 1 nurse practitioner, 2 surgical oncologists, 1 mammogram technician)	Constructivist paradigm; detailed inclusion criteria and recruitment strategy from 4 hospitals; Saturation applied; 4 focus groups; audio recorded and transcribed verbatim; transparent published interview guide; Braun and Clarke thematic analysis based on exercise and health psychology theories	<b>Associated knowledge and attitudes:</b> PA knowledge, PA attitudes; <b>Negative social and environmental influences:</b> Social norms, Environmental norms; <b>PA facilitators:</b> Resources, Clinician education

Author	Year	Location	Intervention	Sample	Method	Themes
Granger et al.	2016	Australia	Physical activity guidelines into oncology practice dealing with people affected by lung cancer	17 professionals (7 doctors, 2 nurses and 8 physical therapists)	9 one-on-one interviews (7 doctors and 2 nurses); 1 focus group (8 physical therapists); transparent published interview guide; Two researcher conducted interviews and analysis; Purposive sampling; e-mail recruitment; duration between 16 and 52 minutes; Audio recorded and field notes taken; transcribed verbatim; saturation applied; line-by-line analysis; content analysis mentioned in the methods (Hsieh and Shannon 2005) but thematic analysis in the abstract; member checking; COREQ standards	<b>Theme 1: Patient Physical and Psychological Influences:</b> Subthemes: Symptoms, Psychological factors, Comorbidities; <b>Theme 2: patient knowledge and past behaviour:</b> Subthemes: Past physical activity behaviour, Patient prioritization and perceived relevance of physical activity, Patient knowledge about physical activity; <b>Theme 3: Clinicians knowledge and beliefs about physical activity:</b> Subthemes: Clinicians belief about physical activity, Education and knowledge, Evidence for physical activity; <b>Theme 4: Workplace culture:</b> Subthemes: Culture of physical activity, Prioritization and time; <b>Theme 5: Healthcare system-environmental and structural influences:</b> Subthemes: Staffing and services; Pathways, protocols and referrals; Integration of the multi-disciplinary team and continuity of care for the patient

Author	Year	Location	Intervention	Sample	Method	Themes
Handberg et al.	2018	Denmark	Professional attitudes towards male cancer survivors (mixed) regarding cancer rehabilitation	58 professionals (52 nurses (2 student nurses included), 3 radiology technicians (1 student included), 3 social and healthcare assistant)	9 focus groups from 3 hospitals, theoretical sampling of participants; Audio recorded and transcribed, field notes made during observations, Interpretative description methodology based on the theoretical framework of Bulmer's (1969) theory of symbolic interactionism, iterative constant comparative manner, NVivo used for analysis, two researchers doing the analysis	Gender perception (Conceptions of Masculinity; Emotional reluctance); Rehabilitation perception (prioritised practice; confined responsibility)
Ijsbrandy et al.	2019	The Netherlands	Physical activity programme implementation in a shared-care model	31 primary health professionals (PHP) (14 GPs and 17 physiotherapist), 39 secondary health professionals (SHP) (13 physicians and surgeons, 12 paramedic, 13 nurse and 1 spiritual counsellor)	31 individual interviews with PHPs; 4 focus groups with 39 SHPs; purposive sampling; interview guide was not published; Interviews about 90 min long; 2 researcher conducting; saturation used; Interviews audio-recorded and transcribed; Atlas.ti used for analysis; Content analysis by Elo et al. Two researchers coded; COREQ standards	Domain of physical activity programmes; Domain of patients; Domain of HCPs; Domain of social setting; Domain of organisation; Domain of law and governance



Author	Year	Location	Intervention	Sample	Method	Themes
Jakobsson et al.	2008	Sweden	Assessment and management of cancer-related symptoms	31 professionals (12 nurses; 6 physicians; 13 mixed professions (physiotherapists, OTs, dietitians; social workers))	8 focus groups; inclusion criteria mentioned; published and transparent interview guide; audio recorded and transcribed interviews; 50-75 min; qualitative content analysis (Krippendorff 1980; Weber 1990); focus groups were moderated by the same person, except for one	<b>Creating a relationship:</b> creating confidence when caregiving, participation, availability, individual care, validation; <b>Understanding of the patient:</b> competence, values; <b>Assessing the Symptom:</b> assessment methods, identifying symptoms using signs, symptom clusters: <b>Cooperating as a Team:</b> Availability and knowledge of each other; Role assignments; Communication
James-Martin et al.	2014	Australia	Information on diet, exercise, and weight management	15 participants (7 professionals: oncology medical specialist, senior oncology nurses, oncology social worker, and oncology dietitian) (6 patients and a survivor: all female group: breast, ovarian and rectal) Numbers do not add up.	Three focus groups with 2 to 6 participants. Moderator was an Oncology Nurse with the presence of an RA. About an hour long. No published interview guide, only topics mentioned. Audio-recorded and transcribed by RA. Thematic analysis based on Saldan'a 2011 and Krueger and Casey 2000. NVivo 8.	Theme 1: Information; Theme 2: Assessment of diet weight and exercise; Theme 3: Patient and practitioner recommendations (Format; Timing of information; Who should provide information)

Author	Year	Location	Intervention	Sample	Method	Themes
Kenyon et al.	2020	UK	Management of upper limb movement impairments (ULMI) after breast cancer treatment	6 physiotherapists (all female)	Hermeneutic phenomenological approach by Heidegger (1962); purposive sample of physiotherapists; broad inclusion criteria; face-to-face, in-depth, semi-structured interviews; published and transparent interview guide; 45 to 70 minutes; transcribed verbatim; IPA; clear audit trail and reflexive diary	Lack of confidence related to treatment of ULMI; Development of confidence through experience; Perceived impact of physiotherapy on patients' quality of life; Practice challenges
McCartney et al.	2011	UK (Cardiff included)	Accessing rehabilitation from AHPs for people with primary high-grade brain tumours	8 professionals (2 GPs, 3 hospice cancer nurse specialists, 2 Macmillan therapy radiographers, 1 oncology nursing sister)	Purposive sample of GPs, hospice nurses, therapy radiographers; Inclusion criteria published; Semi-structured interviews; no published interview guide; audio recorded, and transcribed by one of the authors; inductive thematic analysis; saturation used; three people coded the data; rigour section has some issues - only ethics mentioned and that data was analysed by three researchers	<b>1. Professional knowledge and behaviours:</b> Knowledge of concept of rehabilitation, lack of experience with brain tumours, knowledge of potential AHP role for brain tumour patients, Behaviours/responses to referrals, knowledge of services available; <b>2. Services and systems:</b> Resources of rehabilitation services, Pathways, patient flows and access routes, Categorisation of brain tumour patients; <b>3. The disease and its effects:</b> Rarity and prognosis, Effect on patient behaviours and abilities; <b>4. Solutions to barriers</b>

Author	Year	Location	Intervention	Sample	Method	Themes
Neher et al.	2020	Sweden	Implementation of physical activity and rehabilitation guidelines in routine primary care rehabilitation	48 professionals (32 physiotherapists, 15 occupational therapists, 1 rehabilitation assistant)	7 focus groups (as part of ordinary inter-professional workplace meetings); 4-12 participants per focus groups; 43-55 minutes long interview; semi-structured interviews; transparent and published interview guide; reflexivity included - moderator and researcher and participants relationship considered; audio recorded and transcribed; content analysis in NVivo; two people analysing the data and a third person triangulating.	<b>Limited practice experience:</b> Current practice with cancer survivors; Different or Similar?; Red flags; <b>Uncertainty:</b> Professional Doubts; Physical advice for cancer survivors: Why, Who and How?; Feelings of inadequacy; <b>Being part of a Network:</b> Cooperation within the clinic; Finding the way in the system; Need of specialist
Olsson Moller et al.	2020	Sweden	Individualised cancer rehabilitation for people affected by breast cancer	19 professionals (7 nurses, 1 nurse assistant, 1 physician, 1 psychologist, 5 physiotherapists, 3 social workers, 1 occupational therapist)	Five focus group interviews; 71 and 89 min long; semi-structured interviews, published and transparent interview guide; two authors moderated the groups; audio recorded and transcribed interviews; two authors did main analysis; qualitative content analysis; COREQ standards	<b>1. Varying attitudes towards rehabilitation:</b> Rehabilitation based on medical indicators; Lack of consensus about approach towards rehabilitation; Setting goals for rehabilitation; <b>2. Incongruence in how to identify and meet rehabilitation needs:</b> Identifying signs of vulnerability; Screening for rehabilitation needs; Actions triggered by signs of vulnerability; <b>3. Suboptimal collaboration during cancer treatment:</b> Interprofessional team collaboration; Interdisciplinary collaboration

Author	Year	Location	Intervention	Sample	Method	Themes
Payne et al.	2018	UK; Northern Ireland	6-week individualised behaviour change programme with physical activity and nutritional guidance for non-small cell lung cancer	8 patients and 6 healthcare professionals (4 clinical trials nurse; 1 clinical oncologist and 1 medical oncologist)	Individual semi-structured interviews; transparent and published interview guide; face to face and on telephone interview; Dietitian and PhD student as the interviewer; audio recorded; transcribed verbatim; field notes used; thematic analysis based on Newell and Burnard (2011)	<b>Patient themes:</b> Challenges of living with incurable cancer, Personal and altruistic reasons for participating, Applicability of palliative rehabilitation to self, Barriers and facilitators to adherence, Positive impact on self and others; <b>Healthcare professional themes:</b> Pre-study-mixed perceptions of palliative rehabilitation, Perceived benefits for patients and families, Lessons for future research
Romero-Elías et al.	2020	Spain	Physical activity and physical activity guidance for people affected by colorectal cancer during adjuvant chemotherapy	10 people affected by colorectal cancer; 10 relatives, and 10 healthcare professionals (1 psycho- oncologist; 4 oncologists and 5 nurses)	Individual semi-structured interviews; inclusion and exclusion criteria mentioned; detailed recruitment process; CASP followed for rigour guidance; published and transparent interview guide; interviewer is main author; audio recorded and transcribed verbatim; inductive thematic analysis (Braun and Clarke 2006); rigour by 'critical friends'	<b>Barrier related to ostomy and adjuvant chemotherapy:</b> Difficulties associated with the ostomy, Limitations of the intravenous chemotherapy device, Fatigue and reduced physical fitness, Focusing on cancer and restructuring priorities; <b>Barriers related to perceived lack of support for PA:</b> Families' overprotection, Health professionals' lack of knowledge and time to prescribe PA, Lack of PA services in health centres

Author	Year	Location	Intervention	Sample	Method	Themes
Santa Mina et al.	2015	Canada	Exercise counselling, prescription or assessment of people affected by cancer during and after treatment	13 programme coordinators (4 kinesiologists, 3 rehabilitation scientists, 4 exercise scientists, 1 health researcher, 1 social worker)	Semi-structured interviews with program coordinators; snowball sampling; interview questions developed by research team and pilot tested on research team; interview conducted by research assistant; 30 minutes long; audio recorded transcribed; inductive content analysis; 4 people coding	<b>Program Implementation:</b> Program Initiation (Clinical care extension, Research project expansion, Program champion), Funding, Participant Intake (Avenues of awareness, Health and safety assessment), Active Programming (Monitoring patient exercise progress, HCP involvement, Program composition), Discharge and Follow-up plan; <b>Program enablers:</b> Patient participation (Personalised care, Supportive network, Personal control, Awareness of benefits), Partnerships, Advocacy and support, Program Characteristics; <b>Program Barriers:</b> Lack of Funding, Lack of physician HCP support, Deterrents to participation (Fear and shame, Program location, Competing interests), Disease Progression and Treatment

Author	Year	Location	Intervention	Sample	Method	Themes
Shea et al.	2019	Canada	Physical activity programmes for people affected by cancer and physical activity discussions and counselling	30 professionals (7 oncologists (4 with admin roles), 7 nurses, 6 AHPs, 5 administrators, and 5 physical activity programme leaders (3 nurses, 2 AHPs))	Semi-structured interviews with professionals; stratified purposeful sampling to have a geographically diverse sample; snowball sampling to identify more professionals; inclusion criteria mentioned for services; speaking English was a requirement; interview guide developed by research team, but not published; telephone interviews were conducted; Audio recorded and transcribed verbatim; saturation; 12 to 78 minutes for interviews; inductive constant comparative approach; two coded two interviews and third person reviewed decisions	<b>1. Knowledge and attitudes regarding physical activity promotion and need for programming for cancer survivors</b> (Physical activity knowledge and attitudes; Awareness of need for physical activity programming); <b>2. Implementation barriers</b> (Lack of physical activity discussions and counselling behaviours in the oncology setting; Competing priorities; Lack of expertise, knowledge of benefits and cancer-specific programming; Lack of administrative support and program funding and cost); <b>3. Implementation enablers</b> (Addition of exercise specialist to the oncology healthcare team; Supportive networks; Strength of evidence)

Author	Year	Location	Intervention	Sample	Method	Themes
Smith-Turchyn et al.	2016	Canada	Physical activity promotion to people affected by breast cancer	24 professionals (7 medical oncologists, 5 primary care nurses, 4 radiation oncologists, 2 surgeons, 2 radiation therapists, 1 GP in oncology, 1 nurse practitioner, 1 social worker, 1 dietitian)	Individual semi-structured interviews (21 in person, 2 telephone and 1 videoconference), combination of purposive and snowball sampling, saturation, published and transparent interview guide piloted on the first two participants, 30 min long interviews, audio recorded and transcribed verbatim by an independent transcriptionist, field notes made, descriptive qualitative analysis, 5 transcripts analysed by 2 researchers, code book developed, NVivo 10	Institutional barriers, Health care professional barriers, Perceived patient barriers; Facilitators: Resource and service needs, Patient characteristics
Transforming Cancer Services Team	2017	UK; London	Specialist cancer AHP workforce	11 commissioners	3 focus groups (60-90 minutes long); data was tabulated under 10 categories	Understanding rehabilitation/cancer rehabilitation; Examples of good rehabilitation services; How services are commissioned; How decisions are made about commissioning; Gaps in rehabilitation services; Data collection; Views on Transforming Cancer Services Team commissioning guidance for lymphoedema services; What to include in commissioning guidance for cancer rehabilitation; Supporting implementation of guidance

## Appendix 4: Ethical approval

		
		<b>Health Research Authority</b>
		<b>London - South East Research Ethics Committee</b>
		Barlow House 3rd Floor 4 Minshull Street Manchester M1 3DZ
 29 December 2017		
Dr Tessa Watts		
[REDACTED]		
[REDACTED]		
[REDACTED]		
[REDACTED]		
 Dear Dr Watts		
<b>Study title:</b>	<b>Realist evaluation and economic analysis of cancer rehabilitation services in South Wales (REEACaRS)</b>	
<b>REC reference:</b>	<b>17/LO/2123</b>	
<b>Protocol number:</b>	<b>RIO 031-17</b>	
<b>IRAS project ID:</b>	<b>236999</b>	
 The Proportionate Review Sub-committee of the London - South East Research Ethics Committee reviewed the above application on 15 December 2017.		
<p>We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact <a href="mailto:hra.studyregistration@nhs.net">hra.studyregistration@nhs.net</a> outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.</p>		
<b>Ethical opinion</b>		
<p>On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.</p>		
<b>Conditions of the favourable opinion</b>		
<p>The REC favourable opinion is subject to the following conditions being met prior to the start of the study.</p>		
<p><u>Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.</u></p>		



*Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).*

*Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, [www.hra.nhs.uk](http://www.hra.nhs.uk) or at <http://www.rdforum.nhs.uk>.*

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of management permissions from host organisations.*

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact [hra.studyregistration@nhs.net](mailto:hra.studyregistration@nhs.net). The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### **Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion").

## Approved documents

The documents reviewed and approved were:

Document	Version	Date
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Permission from Macmillan]	1	22 August 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		01 August 2017
Interview schedules or topic guides for participants [Patient interview guide]	2	10 November 2017
Interview schedules or topic guides for participants [Service provider interview guide]	2	10 November 2017
IRAS Application Form [IRAS_Form_30112017]		30 November 2017
IRAS Checklist XML [Checklist_30112017]		30 November 2017
Letter from sponsor [Letter from sponsor]	2	30 November 2017
Letters of invitation to participant [Patient invitation letter [REDACTED]]	3	27 November 2017
Letters of invitation to participant [Service providers invitation letter [REDACTED]]	2	22 November 2017
Other [Peer review]	1	23 November 2017
Other [Response slip]	3	27 November 2017
Other [Response slip [REDACTED]]	3	27 November 2017
Other [CV [REDACTED]]	1	03 November 2017
Other [CV [REDACTED]]	1	04 November 2017
Participant consent form [Companion consent [REDACTED]]	3	22 November 2017
Participant consent form [Patient consent Phase 2 [REDACTED]]	3	22 November 2017
Participant consent form [Patient consent Phase 3 [REDACTED]]	3	22 November 2017
Participant consent form [Patient consent Phase 3 [REDACTED]]	3	22 November 2017
Participant consent form [Service provider consent [REDACTED]]	3	22 November 2017
Participant information sheet (PIS) [Companion IS [REDACTED]]	4	27 November 2017
Participant information sheet (PIS) [PIS Phase 2 [REDACTED]]	4	27 November 2017
Participant information sheet (PIS) [PIS Phase 3 [REDACTED]]	3	22 November 2017
Participant information sheet (PIS) [PIS Phase 3 [REDACTED]]	3	22 November 2017
Participant information sheet (PIS) [Service providers IS [REDACTED]]	4	27 November 2017
Research protocol or project proposal [REEACaRS protocol]	6	27 November 2017
Summary CV for Chief Investigator (CI) [CV Dr Tessa Watts]	1	30 March 2017
Summary CV for student [Judit Katalin Csontos CV]	1	27 November 2017
Summary CV for supervisor (student research) [Professor Deborah Fitzsimmons]	1	20 October 2017
Summary, synopsis or diagram (flowchart) of protocol in non-technical language [Protocol flowchart]	2	17 November 2017
Validated questionnaire [Resource Use Measure Questionnaire]	2	
Validated questionnaire [HNA questionnaire]		
Validated questionnaire [EQ5D-5L and FACIT-F]		



### **Membership of the Proportionate Review Sub-Committee**

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### **After ethical review**

#### Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

### **User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

### **HRA Training**

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

**17/LO/2123**

**Please quote this number on all correspondence**

Yours sincerely



**Chair**

Email: [nrescommittee.london-southeast@nhs.net](mailto:nrescommittee.london-southeast@nhs.net)

*Enclosures: List of names and professions of members who took part in the review  
"After ethical review – guidance for researchers"*

*Copy to:*



**London - South East Research Ethics Committee**

**Attendance at PRS Sub-Committee of the REC meeting on 15 December 2017**

**Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Professor David Caplin	Physicist	Yes	Chair
Professor Atholl Johnston	Professor of Clinical Pharmacology	Yes	
Ms Brigid Tucker	Head of Policy & Communications, General Osteopathic Council	Yes	

**Also in attendance:**

<i>Name</i>	<i>Position (or reason for attending)</i>
Ms Julie Acourt	REC Assistant
Mrs Margaret Hutchinson	REC Manager

## Appendix 5: Ethical approval amendment



# Health Research Authority

London - South East Research Ethics Committee

Barlow House  
3rd Floor  
4 Minshull Street  
Manchester  
M1 3DZ

Tel: 0207 104 8002

**Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.**

17 April 2019

**Miss Judit Katalin Csontos**  
**Full time PhD Student**

[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]

Dear Miss Csontos

<b>Study title:</b>	<b>Realist evaluation and economic analysis of cancer rehabilitation services in South Wales (REEACaRS)</b>
<b>REC reference:</b>	<b>17/LO/2123</b>
<b>Protocol number:</b>	<b>RIO 031-17</b>
<b>Amendment number:</b>	<b>Amendment 1</b>
<b>Amendment date:</b>	<b>26 February 2019</b>
<b>IRAS project ID:</b>	<b>236999</b>

The above amendment was reviewed by the Sub-Committee in correspondence.

### **Ethical opinion**

Approval was sought for a change in Sponsor.

There were no ethical issues raised.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.



### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Cardiff University Insurance]		02 July 2018
Letter from sponsor [Cardiff University Sponsorship]		21 February 2019
Letters of invitation to participant [Patient - ██████████]	7	15 February 2019
Letters of invitation to participant [Patient - ██████████]	7	15 February 2019
Letters of invitation to participant [Service Provider ██████████]	6	15 February 2019
Letters of invitation to participant [Service Provider ██████████]	5	15 February 2019
Notice of Substantial Amendment (non-CTIMP)	Amendment 1	26 February 2019
Other [Response Slip ██████████]	6	14 February 2019
Other [Response Slip ██████████]	6	14 February 2019
Other [Swansea University Sponsorship Transfer ]		13 February 2019
Other [Updated IRAS form with new Sponsor & Acedemic Supervisor]		08 April 2019
Participant consent form [Companion - Phase 2 ██████████]	6.	14 February 2019
Participant consent form [Companion - Phase 2 ██████████]	6	14 February 2019
Participant consent form [Patient - Phase 2 ██████████]	6	14 February 2019
Participant consent form [Patient - Phase 2 ██████████]	6	14 February 2019
Participant consent form [Patient - Phase 3 ██████████]	6	14 February 2019
Participant consent form [Patient - Phase 3 ██████████]	6	14 February 2019
Participant consent form [Service Provider - Phase 2 ██████████]	6	14 February 2019
Participant consent form [Service Provider - Phase 2 ██████████]	6	14 February 2019
Participant information sheet (PIS) [Companion - Phase 2 ██████████]	8	15 February 2019
Participant information sheet (PIS) [Companion - Phase 2 ██████████]	8	15 February 2019
Participant information sheet (PIS) [Patient - Phase 2 ██████████]	8	15 February 2019
Participant information sheet (PIS) [Patient - Phase 2 ██████████]	8	15 February 2019
Participant information sheet (PIS) [Patient - Phase 3 ██████████]	7	15 February 2019
Participant information sheet (PIS) [Patient - Phase 3 ██████████]	7	15 February 2019
Participant information sheet (PIS) [Service Provider - Phase 2 ██████████]	8	15 February 2019
Participant information sheet (PIS) [Service Provider - Phase 2 ██████████]	8	15 February 2019
Research protocol or project proposal	7.1	26 February 2019
Summary CV for supervisor (student research) [Dominic Roche]		

### Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

**Working with NHS Care Organisations**

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**HRA Learning**

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: <https://www.hra.nhs.uk/planning-and-improving-research/learning/>

<b>17/LO/2123:</b>	<b>Please quote this number on all correspondence</b>
--------------------	---

Yours sincerely



**Chair**

**E-mail:** [nrescommittee.london-southeast@nhs.net](mailto:nrescommittee.london-southeast@nhs.net)

**Enclosures:** List of names and professions of members who took part in the review



**London - South East Research Ethics Committee**

**Attendance at Sub-Committee of the REC meeting**

**Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
██████████	Retired Solicitor	Yes	
██████████	Reader in Biostatistics	Yes	

**Also in attendance:**

<i>Name</i>	<i>Position (or reason for attending)</i>
██████████	Approvals Administrator

## Appendix 6: Letter of Access No1



**GIG**  
CYMRU  
**NHS**  
WALES

[REDACTED]  
[REDACTED]  
[REDACTED]

☎ Direct line/Rhif llinell union: [REDACTED]  
📠 Fax/facs: [REDACTED]  
✉ [REDACTED]  
Research & Development Department  
[REDACTED]  
[REDACTED]  
[REDACTED]

23 February 2018

Miss Judit Csontos  
PhD Student  
College of Human and Health Sciences  
[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]

Dear Miss Csontos

Letter of Access - [REDACTED]

Research Study  
IRAS REF: 236999 – Realist evaluation and economic analysis of cancer rehabilitation services in South Wales (REEACaRS)

Research Activities – Full outline on Research Passport

This letter should be presented to each participating organisation before you commence your research at that site. The participating organisation is [REDACTED]  
[REDACTED]

In accepting this letter, [REDACTED] confirms your right of access to conduct research through their organisation for the purpose and on the terms and conditions set out below. This right of access commences on 23 February 2018 and ends on 31<sup>st</sup> December 2020 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from [REDACTED] *Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving confirmation from the Health Board (via the R&D Department) of their agreement to conduct the research.*

[REDACTED]

Version 2.3, August 2013  
Research in the NHS: HR Good Practice Resource Pack

Page 1 of 3

317 | Page



The information supplied about your role in research at this Health Board has been reviewed and you do not require an honorary research contract with [REDACTED]. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to [REDACTED] premises. You are not entitled to any form of payment or access to other benefits provided by the Health Board to employees and this letter does not give rise to any other relationship between you and the Health Board, in particular that of an employee.

While undertaking research through [REDACTED] you will remain accountable to your substantive employer, Swansea University but you are required to follow the reasonable instructions of the [REDACTED] or those instructions given on her behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by the organisation(s) in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with [REDACTED] policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with [REDACTED] in discharging its/their duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on the organisations premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and each organisation prior to commencing your research role at that organisation.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the organisations







premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that the organisation(s) do not accept responsibility for damage to or loss of personal property.

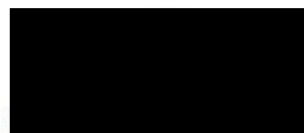
This Health Board may revoke this letter and may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of the Health Board or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you **MUST** stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

No organisation will indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in each participating organisation and the R&D office in this Health Board.




Yours sincerely







R&D Administrator



## Appendix 7: Letter of Access No2



Welsh Blood Service  
Gwasanaeth Gwaed Cymru



*Correspondence to: Mrs Sarah Townsend, Research and Development Manager, [Redacted]  
Research & Development Office, [Redacted]  
[Redacted]  
[Redacted]*

**PRIVATE AND CONFIDENTIAL**

Miss Judit Csontos  
[Redacted]  
[Redacted]  
[Redacted]

11<sup>th</sup> April 2018

Dear Miss Csontos,

**Letter of access for research**

This letter confirms your right of access to conduct research through [Redacted] for the purpose and on the terms and conditions set out below. This right of access commences on 11<sup>th</sup> April 2018 and ends on 31<sup>st</sup> December 2020 unless terminated earlier in accordance with the clauses below.







You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at [Redacted] has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to [Redacted] premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through [Redacted] you will remain accountable to your employer, Swansea University, but you are required to follow the reasonable instructions of the head of the relevant NHS Department/research supervisor in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

[Redacted]  
[Redacted]



Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with [REDACTED] policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with [REDACTED] in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on [REDACTED] premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<https://www.gov.uk/government/publications/confidentiality-nhs-code-of-practice>) and the Data Protection Act 1998 (<http://www.legislation.gov.uk/ukpga/1998/29/contents>). Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that [REDACTED] accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of [REDACTED] or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

[REDACTED] will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely,

[REDACTED]

Research and Development Manager and Sponsor Representative

[REDACTED]

cc: HR office, [REDACTED]  
[REDACTED] PGR Academy Manager, Human and Health Sciences, Swansea University



## Appendix 8: Operational definitions for secondary analysis

Variable	Operational definition	Level of measurement
Episode	A 12-week long rehabilitation period. One patient can attend numerous episodes.	Categorical data
Gender	Patients' declared gender. (Male or female)	Categorical data
Cancer diagnosis	The latest primary diagnosis the patient received treatment for.	Categorical data
Scheme	The mode of therapy most appropriate for the patient based on his/her initial assessment. Scheme includes Tai Chi, circuit and hydrotherapy classes, or one-to-one sessions.	Categorical data
FACIT-F	13-item measure of fatigue scored from 0 to 52. Pre and post rehabilitation data is available.	Continuous data
TUAG	Functional mobility test measured in seconds. The shorter period of time it takes to complete the task, the better mobility is. Pre and post rehabilitation data is available.	Continuous data
Quality of life scale	A simple measure of quality of life similar to a VAS scale. Patients can rate their health from 0 to 100. 100 refers to best imaginable health. Pre and post rehabilitation data is available.	Continuous data
Pain scale	A simple measure of cancer-related pain. Score is an average of worst experienced pain and pain on assessment. It ranges from 0 to 10. Ten means extreme pain. Pre and post rehabilitation data is available.	Continuous data
Shortness of Breath (SOB)	A simple VAS type measure of breathlessness. Score is an average of worst experienced breathlessness and dyspnoea on assessment. It ranges from 0 to 10. Ten refers to extreme breathlessness. Pre and post rehabilitation data is available.	Continuous data
Discharge codes (DC_CODE)	Eighteen different codes referring to the reason why the patient was discharged, or the episode ended. Usually 2 to 4 different codes were allocated to each person. Codes include refused scheme, inappropriate referral, disengaged, and health deterioration among others. Each discharge code were ordered into a binary variable.	Categorical data

## Appendix 9: Healthcare professional interview guide

### Service provider Interview guide

**Study Title: Realist evaluation and economic analysis of cancer rehabilitation services in South Wales (REEACaRS)**

**Phase 2: face to face, individual, audio recorded interview with service providers**

**Principal Investigator: Judit Katalin Csontos**

#### Interviewee – Interviewer Introduction

The aim of this interview is to look at how cancer rehabilitation services work in South Wales. I would like to explore what rehabilitation means for patients and for you (healthcare professionals) and what value cancer rehabilitation has for you. I aim to investigate what helps patients to benefit from the services and what barriers they face in getting appropriate help for their needs. Your answers can help us understand what works in cancer rehabilitation and how it works. Better understanding of how the services operate can identify achievements and problems and help improving cancer rehabilitation. I would like you to tell me anything that is important for you. There are no right or wrong answers.

General questions:

How are you?

What is your position at your institution?

How long have you been working for this institution?

Research question	Interview questions
What do patients and service providers understand as cancer rehabilitation?	Could you explain to me what cancer rehabilitation means for you?  Could you tell me what your expectations of cancer rehabilitation are as a professional?
What are the barriers and facilitators of cancer rehabilitation?	Could you tell me what therapies or support do you offer at your institution?  What principles, theories or guidelines do you follow in the therapies and support of cancer patients? Could you explain it to me why?  What are the most common referral routes (eg. consultant, General Practitioner, self-referral)?

IRAS: 236999 – REEACaRS – Service provider Interview Guide – Phase 2 – v 2 – 10.11.2017



<p>What are the barriers and facilitators of cancer rehabilitation?</p>	<p>In your experience what are the most common cancer sites and site related problems patients visit cancer rehabilitation with?</p> <p>Could you tell me what type of patient assessment do you use?</p> <ul style="list-style-type: none"> <li>• Why do you use this type of patient assessment?</li> </ul> <p>Could you tell me what the difficulties you have to face in providing patient care are?</p> <ul style="list-style-type: none"> <li>• What do you think the sources of these difficulties are?</li> <li>• Could you tell me about any institutional difficulties you have to face?</li> <li>• Could you tell me about any patient related difficulties you have to face?</li> </ul> <p>What do you think about the 4 level model of rehabilitation?</p> <ul style="list-style-type: none"> <li>• Do you think your work is guided by this model?</li> </ul>
<p>What value cancer rehabilitation has from patients' and service providers' perspective?</p>	<p>Could you tell me what the short-term benefits of therapy and support are?</p> <p>What are the long-term benefits of therapy and support?</p> <p>What do you think what aspects of health and well-being the support you provide can affect?</p>

## Appendix 10: Interview guide for people affected by cancer

### Patient Interview guide

**Study Title: Realist evaluation and economic analysis of cancer rehabilitation services in South Wales (REEACaRS)**

**Phase 2: face to face, individual, audio recorded interview**

**Principal Investigator: Judit Katalin Csontos**

#### Interviewee – Interviewer Introduction

The aim of this interview is to look at how cancer rehabilitation services work in South Wales. I would like to explore what rehabilitation means for you and what value cancer rehabilitation has for you. We aim to investigate what helps you make the most of the services and what barriers you have to face in accessing rehabilitation and getting appropriate help for your needs. These interviews will help us to better understand what works in cancer rehabilitation and how it works. Better understanding of how cancer rehabilitation works for you can identify the achievements and problems of the services and can help to improve them. Therefore I would like you to tell me anything that is important for you. There are no right or wrong answers.

#### General questions:

How are you?

How has your day been?

Research question	Interview questions
What do patients and service providers understand as cancer rehabilitation?	Could you tell me how you learnt about cancer rehabilitation?  What did you think cancer rehabilitation was when you started it?  Could you tell me what cancer rehabilitation means for you now?
What are the barriers and facilitators of cancer rehabilitation?	Could you tell me what kind of problems you had with your health and well-being related to your cancer or treatment that you needed help with?  Could you tell me what bothered you related to your health?

IRAS: 236999 – REEACaRS – Patient Interview Guide – Phase 2 – v 2 – 10.11.2017

<p>What are the barriers and facilitators of cancer rehabilitation?</p>	<p>What kind of help have you got from consultants, nurses, healthcare professionals, or health and social care services?</p> <ul style="list-style-type: none"> <li>• What do you think which aspects of care was helpful (eg. patient information, contact with professionals, exercise)?</li> <li>• Could you tell me in what way was it helpful (eg. getting fit, help with independence)?</li> <li>• How did the care provided live up to your expectations?</li> <li>• Who provided help?</li> <li>• How did you get in contact with them?</li> <li>• Was there anything that made it hard for you to access help or get in contact with a professional?</li> <li>• Could you tell me what made it hard for you to access the cancer rehabilitation service?</li> </ul> <p>Do you think this help was enough to ease the problem?</p> <ul style="list-style-type: none"> <li>• What more do you think could be done (eg. more information, more sessions)?</li> <li>• What do you think, why you did not get enough help?</li> </ul> <p>After rehabilitation what bothers you about your health condition?</p>
<p>What value cancer rehabilitation has from patients' and service providers' perspective?</p>	<p>How did cancer rehabilitation affect your life, everyday activities?</p> <p>What kind of permanent changes the intervention you received evoke in your lifestyle?</p> <p>What do you think in what way cancer rehabilitation was valuable for you?</p>

## Appendix 11: Invitation letter for healthcare professionals



Judit Katalin Csontos  
School of Healthcare Sciences  
Cardiff University  
Eastgate House,  
Cardiff, CF24 0AB  
Contact Telephone Number: [REDACTED]  
E-mail: CsontosJK@cardiff.ac.uk

Date:

Dear ...,

### Letter of Invitation

**Study Title: Realist evaluation and economic analysis of cancer rehabilitation services in South Wales (REEACaRS)**

Principal Investigator: Judit Katalin Csontos

My name is Judit Katalin Csontos and I am a Postgraduate Research Student at Cardiff University.

My research interest is in rehabilitation and I am conducting a study funded by Macmillan Cancer Support, Swansea University and Cardiff University to look at how cancer rehabilitation services work in South Wales. Knowing how services work and for whom can help us identify the strength and weaknesses of cancer rehabilitation. Recognising the areas to improve can help with providing high quality care for everyone. To investigate all aspects of cancer rehabilitation in South Wales I am asking for patients and healthcare professionals to help and I would like to invite you to take part in this project.

As part of the project, I would like to interview healthcare professionals to ask you what you think about how cancer rehabilitation services work. I attach an information sheet to this letter, which gives you further details about the project and participation. Please, take time to read and consider the information provided about the study. If you are happy with the information and would like to take part in the study, please contact me on the above details

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(telephone or e-mail). When you contact me, we can arrange a suitable date, time and place for the interviews.

Please do not hesitate to contact me on the above number or e-mail address, if you have any questions or concerns about this project. I will be happy to answer any questions you may have if you would like to discuss the study and what your involvement would be. You can also contact the academic supervisors of the project on the details provided below.

Dr Tessa Watts (PhD, Msc, Bsc, RN)

E-mail: [wattst1@cardiff.ac.uk](mailto:wattst1@cardiff.ac.uk)

Dr Dominic Roche (PhD, BSc, RN)

Telephone: +44(0)2920687801 E-mail: [roched1@cardiff.ac.uk](mailto:roched1@cardiff.ac.uk)

Thank you for taking the time to read this letter and for considering participating in this project.

Yours faithfully,

Judit Katalin Csontos

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## Appendix 12: Healthcare professional information sheet



### Service Provider Information Sheet

**Study Title: Realist evaluation and economic analysis of cancer rehabilitation services in South Wales (REEACaRS)**

Phase 2: face to face, individual, audio recorded interview with service providers

Principal Investigator: Judit Katalin Csontos

May I introduce myself? I am Judit Katalin Csontos a Postgraduate Research Student at Cardiff University and my interest is in cancer rehabilitation. At the moment I am looking at how cancer rehabilitation services work in South Wales. You are invited to take part in this research study, because you have been providing cancer rehabilitation in South Wales. Please take time to read and consider the information given below. To make an informed decision about whether to participate or not, please feel free to discuss the study and participation with your family, friends, members of your healthcare team or anyone you feel comfortable talking about it. If you have any questions or concerns about taking part in this project, you can contact me, Judit Katalin Csontos, or my academic supervisors, Dr Tessa Watts or Dr Dominic Roche directly. Our contact details can be found at the end of this information sheet.

#### What is the purpose of the study?

The purpose of this study is to look at how cancer rehabilitation services work in South Wales. Cancer rehabilitation helps with the side effects of cancer and its treatment with the involvement of different healthcare professionals. In South Wales cancer rehabilitation has not been thoroughly investigated. To provide high quality care for everyone it is important to know how services work. In this part of the study (Phase 2) participants will be encouraged to tell what they think how cancer rehabilitation works in the form of a face to face, audio recorded interview.

#### Who is organising and funding the study?

The project is funded by Macmillan Cancer Support, Swansea University and Cardiff University.

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**Why have I been invited to take part?**

You have been invited, because you have been providing care or taking part in the organisation and coordination of cancer rehabilitation in South Wales

**Do I have to take part?**

No, you do not have to take part. Participation in the study is entirely voluntary and it is your choice. Before you make a decision, please read this information sheet thoroughly and discuss participation with anyone who you feel comfortable talking about it. If there is any information that is not clear, please contact me directly. If you decide not to take part, this will not affect your care in any way.

**What will happen if I decide to take part?**

If you choose to participate in the study you will be interviewed by me in person on one occasion. Questions will be asked about what you think how cancer rehabilitation works in South Wales.

After reading this information sheet, if you would like to be interviewed you can contact me on the details at the end of this information sheet and an appropriate date, time and place will be agreed for the face to face, audio recorded interview.

You can choose where you would like to have the interview. You can opt to be interviewed in one of the quiet rooms at School of Healthcare Sciences, Cardiff University or at your own home. If you decide to come to the University, reasonable travel and parking expenses will be reimbursed. However, if it is more suitable for you, you can choose to be interviewed at your own home. In that case the researcher will travel to your home.

On the day of the interview you will receive a consent form and you can ask any questions related to the study from me before signing it. The interview will take a maximum of 60 minutes during a working day. With your permission interviews will be voice recorded and typed up. Your participation is confidential, so I will ensure that any identifying information, including your name, is removed from the typed up notes.

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**What are the potential disadvantages of participation in the study?**

During the interviews sensitive topics about healthcare and your workplace might come up. All information during the interviews will be treated in a confidential way and no identifiable data will be used during the study and dissemination.

During the interviews if you cannot carry on, another date which is suitable for you can be set to finish the interview. You are also free to withdraw from the study at any time.

**What are the potential advantages of participation in the study?**

This study might not benefit you directly, although it can help to understand how cancer rehabilitation services work in South Wales. If the operation of services is better understood, it can give information on how to improve cancer rehabilitation and provide the highest quality care.

**Will my participation be kept confidential?**

Yes, it will. Ethical and legal practices will be followed to ensure confidentiality. All identifiable names and information will be removed and participant identifier numbers will be used instead. All data, voice recordings, typed up notes will be kept on a password secured computer at School of Healthcare Sciences, Cardiff University. All the paper copies of the typed up notes will be kept in a lockable filing cabinet with sole access to the researcher at the School of Healthcare Sciences, Cardiff University. All voice recordings and typed up notes will be stored for 15 years from the data collection at Cardiff University. After 15 years all data will be destroyed.

During the interview if any practice that puts patients at risk is reported, I have the professional obligation to bring this to the attention of the gatekeepers of the study sites. If this happens, data will not be included in the research.

**Who will be informed of my participation?**

Only the researcher will know about your participation. In the interview transcripts all names will be changed and pseudonymised to provide anonymity.

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**What happens when the research study ends?**

Anonymised data will be used as part of a PhD thesis. The findings of the study will be submitted for publication in academic and professional journals and might be presented at local meetings for healthcare professionals and at academic conferences. Some parts of the interview might be directly quoted in publications, but these will be anonymous. You can also have a summary of the findings, if you would like to know the results.

**Who has reviewed this study?**

This study has been reviewed by the academic supervisors of the study, the Research Governance of Swansea University and it has received a favourable opinion from London – South East Research Ethics Committee.

This study has also received an approval from the Research and Development department of



**What if I have a complaint?**

If you have any complaints about the study, please contact Research Governance at Cardiff University on the details stated at the end of this information sheet.

Thank you very much for considering taking part in this study.



For further information, please contact:

Principal investigator/researcher:

Miss Judit Katalin Csontos (Msc, Bsc PT)

PhD Student, School of Healthcare Sciences, Cardiff University

Eastgate House, 35-43 Newport Road, Cardiff University, Cardiff  
CF24 0AB

24 hour answer phone:  E-mail: [CsontosJK@cardiff.ac.uk](mailto:CsontosJK@cardiff.ac.uk)

Academic supervisors:

Dr Tessa Watts (PhD, Msc, Bsc, RN)

Senior Lecturer, School of Healthcare Sciences, Cardiff University  
Eastgate House, 35-43 Newport Road, Cardiff University, Cardiff  
CF24 0AB

E-mail: [wattst1@cardiff.ac.uk](mailto:wattst1@cardiff.ac.uk)

Dr Dominic Roche (PhD, BSc, RN)

Lecturer: Adult Nursing, School of Healthcare Sciences, Cardiff University  
Ty Dewi Sant, Heath Campus, Cardiff  
CF14 4XN

24 hour answer phone: +44(0)2920687801 E-mail: [roched1@cardiff.ac.uk](mailto:roched1@cardiff.ac.uk)

Research Governance:

Research and Innovation Services  
Cardiff University  
7<sup>th</sup> Floor, McKenzie House  
30-36 Newport Road  
Cardiff  
CF24 0DE


Tel: +44(0)29 2087 9131


E-mail: [resgov@cardiff.ac.uk](mailto:resgov@cardiff.ac.uk)


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## Appendix 13: Healthcare professional consent form







**Service Provider Consent Form**

**Study Title: Realist evaluation and economic analysis of cancer rehabilitation services in South Wales (REEACaRS)**

Phase 2: face to face, individual, audio recorded interviews with service providers

Principal Investigator: Judit Katalin Csontos

Participant Identification Number: \_\_\_\_\_

Please read the statements carefully and initial the ones you consent to.

	Please initial the boxes to indicate consent
I confirm that I have read and understood the <b>Service Provider Information Sheet</b> dated (version) for the above project. I have had the opportunity to consider the information stated in the Participant Information Sheet, ask questions and I have had these answered satisfyingly.	
I understand that my participation is entirely voluntary and that I am free to withdraw from the study at any time without giving any further explanation. I understand that my withdrawal will not affect any care that I receive.	
I agree to take part in a face to face, individual, audio recorded interview for the above study.	
I understand that the information collected during the course of the audio recorded interview will be confidential and anonymised.	
I understand that information from the audio recorded interview will be transcribed (typed up) and anonymised by the researcher. I give permission for the researcher to have access to this information.	
I understand that this anonymised transcript will be read and analysed by the researcher and a second reviewer. I give permission for the researcher and the second reviewer to analyse this data.	

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	Please initial the boxes to indicate consent
I agree to the findings of the analysis (including anonymised quotes) being used in the PhD Thesis and for publication in any peer-reviewed academic and professional journals and for presentations at conferences.	
I agree to be re-contacted by the researcher with a summary of the findings of this study.	

**Name of Participant:** \_\_\_\_\_

**Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

Name of Researcher	Date (dd/mm/yyyy)	Signature



## Appendix 14: Invitation letter for people affected by cancer



Judit Katalin Csontos  
School of Healthcare Sciences  
Cardiff University  
Eastgate House,  
Cardiff, CF24 0AB

Contact Telephone Number: [Redacted]  
E-mail: CsontosJK@cardiff.ac.uk

Date:

Dear Sir or Madam,

### Letter of Invitation

**Study Title: Realist evaluation and economic analysis of cancer rehabilitation services in South Wales (REEACaRS)**

Principal Investigator: Judit Katalin Csontos

My name is Judit Katalin Csontos and I am a Postgraduate Research Student at Cardiff University.

My research interest is in rehabilitation and I am conducting a research study funded by Macmillan Cancer Support, Swansea University and Cardiff University to look at how cancer rehabilitation services work in South Wales. Knowing how services work and for whom can help us identify the strength and weaknesses of cancer rehabilitation. Recognising the areas to improve can help with providing high quality care for everyone. To investigate all aspects of cancer rehabilitation in South Wales I am asking for people to help and I would like to invite you to take part in this project.

There are two ways you can help:

- You can choose to take part in a face to face, audio recorded interview on one occasion after your last rehabilitation appointment. During the interview you can tell me about your experiences with cancer rehabilitation. The interview will take a maximum of 60 minutes during a weekday at a time and date most suitable for you.

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- You can choose to fill questionnaires out on two separate occasions (one if you decide to take part and one after your last rehabilitation appointment). In the questionnaire I will ask about your employment status, if you or a family member had to take time off due to any side effects of cancer and its treatment you experienced, GP visits and about how much it costs you to travel to rehabilitation.

You can choose either to take part in the interview or the questionnaires or both.

If you would like to learn more about this study and the different ways you can help us, please complete, sign and return the attached response slip using the freepost envelope you received with this letter.

Please, indicate in which part of the study you are interested in (interview, questionnaire or both). Once I received the response slip I will make contact with you in a way preferred for you (telephone or e-mail) and I will send you a detailed information sheet. You can also indicate your interest and ask questions by contacting me directly on the details provided with this letter (telephone or e-mail).

Please take some time to consider participation in this study. Please do not hesitate to contact me on the above number or e-mail address, if you have any questions or concerns about this project. I will be happy to answer any questions you may have if you would like to discuss the study and what your involvement would be. You can also contact the academic supervisors of the project on the details provided below.

**Dr Tessa Watts (PhD, MSc, BSc, RN)**

E-mail: [wattst1@cardiff.ac.uk](mailto:wattst1@cardiff.ac.uk)

**Dr Dominic Roche (PhD, BSc, RN)**

Telephone: +44(0)2920687801 E-mail: [roched1@cardiff.ac.uk](mailto:roched1@cardiff.ac.uk)

Thank you for taking the time to read this letter and for considering participating in this project.

Yours faithfully,

Judit Katalin Csontos

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## Appendix 15: Response slip

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**Response slip**

**Study Title: Realist evaluation and economic analysis of cancer rehabilitation services in South Wales (REEACaRS)**

Principal Investigator: Judit Katalin Csontos

If you are interested in our study and would like to know more about participation in either the audio recorded interview (Phase 2) or filling out questionnaires at two time points (Phase 3), please complete and return this response slip in the freepost envelope provided to the researcher at Cardiff University. After receiving your response the researcher will contact you in a way you prefer. You can also indicate your interest or ask questions by contacting the researcher on the details given on the invitation letter.

Please, tick which part of the study you are interested in.

Audio recorded interview ☐                      Questionnaires ☐                      Both ☐

Full name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

Please, tick your preferred way of contacting and give us your details.

Contact Telephone Number: \_\_\_\_\_ ☐

E-mail: \_\_\_\_\_ ☐

Please indicate the best time for you to be contacted by the researcher.

Day: \_\_\_\_\_ Time: \_\_\_\_\_ AM/PM

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Please return in Freepost envelope provided to:**

Judit Katalin Csontos *Postgraduate Research Student, Cardiff University*

Contact Telephone Number: XXXXXXXXXX

E-mail: CsontosJK@cardiff.ac.uk

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## Appendix 16: Participant Information Sheet



### Participant Information Sheet

**Study Title: Realist evaluation and economic analysis of cancer rehabilitation services in South Wales (REEACaRS)**

**Phase 2: face to face, individual, audio recorded interview**

**Principal Investigator: Judit Katalin Csontos**

May I introduce myself? I am Judit Katalin Csontos a Postgraduate Research Student at Cardiff University and my interest is in cancer rehabilitation. At the moment I am looking at how cancer rehabilitation services work in South Wales. You are invited to take part in this research study, because you have been attending cancer rehabilitation. Please take time to read and consider the information given below. To make an informed decision about whether to participate or not, please feel free to discuss the study and participation with your family, friends, members of your healthcare team or anyone you feel comfortable talking about it. If you have any questions or concerns about taking part in this project, you can contact me, Judit Katalin Csontos, or my academic supervisors, Dr Tessa Watts or Dr Dominic Roche directly. Our contact details can be found at the end of this information sheet.

#### **What is the purpose of the study?**

The purpose of this study is to look at how cancer rehabilitation services work in South Wales. Cancer rehabilitation helps with the side effects of cancer and its treatment with the involvement of different healthcare professionals. In South Wales cancer rehabilitation has not been thoroughly investigated. To provide high quality care for everyone it is important to know how services work. In this part of the study (Phase 2) participants will be encouraged to tell their story and experiences about cancer rehabilitation in the form of a face to face, audio recorded interview.

#### **Who is organising and funding the study?**

The project is funded by Macmillan Cancer Support, Swansea University and Cardiff University.

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**Why have I been invited to take part?**

You have been invited, because you have started taking part in rehabilitation related to your cancer diagnosis.

**Do I have to take part?**

No, you do not have to take part. Participation in the study is entirely voluntary and it is your choice. Before you make a decision, please read this information sheet thoroughly and discuss participation with anyone who you feel comfortable talking about it. If there is any information that is not clear, please contact me directly. If you decide not to take part, this will not affect your care in any way.

**What will happen if I decide to take part?**

If you choose to participate in the study you will be interviewed by me in person on one occasion after your last rehabilitation appointment. Questions will be asked about your cancer rehabilitation experience.

After reading this information sheet, if you would like to be interviewed, we will discuss in what way (telephone calls or e-mail) you would like me to keep in touch during your rehabilitation journey and the expected finish date of your rehabilitation. After your last rehabilitation appointment I will contact you and an appropriate date, time and place will be agreed for the face to face, audio recorded interview.

You can choose where you would like to have the interview. You can opt to be interviewed in one of the quiet rooms at School of Healthcare Sciences, Cardiff University or at your own home. If you decide to come to the University, reasonable travel and parking expenses will be reimbursed. However, if it is more suitable for you, you can choose to be interviewed at your own home. In that case the researcher will travel to your home. You are very welcome to have a companion with you at the interview for support if you wish.

On the day of the interview you will receive a consent form and you can ask any questions related to the study from me before signing it. The interview will take a maximum of 60 minutes during a working day. With your permission interviews will be voice recorded and typed up. Your

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participation is confidential, so I will ensure that any identifying information, including your name, is removed from the typed up notes.

After the interview with your permission I will also access your hospital notes. Your hospital notes, your care team has administered as part of your routine care, include: questionnaires about your current health and rehabilitation needs.

**What are the potential disadvantages of participation in the study?**

Questions will be asked about your illness, which you may find upsetting. If you get upset at any point during the interviews, you can stop. I can support you and I can give you advice on who to contact with any problems. If you need any longer term care or support, I can give you the contact details of your healthcare team or other support services.

During the interviews if you feel like you cannot carry on, another date which is suitable for you can be set to finish the interview. You are also free to withdraw from the study at any time and without any explanation, it will not affect any care you receive.

**What are the potential advantages of participation in the study?**

This study might not benefit you directly, although talking about your experiences and telling your story can help to understand how cancer rehabilitation services work in South Wales. If the operation of services is better understood, it can give information on how to improve cancer rehabilitation and provide the highest quality care.

**Will my participation be kept confidential?**

Yes, it will. Ethical and legal practices will be followed to ensure confidentiality. All identifiable names and information will be removed and participant identifier numbers will be used instead. All data, voice recordings, typed up notes will be kept on a password secured personal computer drive at School of Healthcare Sciences, Cardiff University. All the paper copies of the typed up notes will be kept in a lockable filing cabinet with sole access to the researcher at the School of Healthcare Sciences, Cardiff University. All voice recordings and typed up notes will be stored for 15 years from the data collection at Cardiff University. After 15 years all data will be destroyed.

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During the interview if any practice that puts patients at risk is reported, I have the professional obligation to bring this to the attention of the gatekeepers of the study sites. If this happens, data will not be included in the research.

**Who will be informed of my participation?**

Only with your consent a member of the cancer rehabilitation team will be contacted for your hospital notes. This is only necessary to access information. Your partaking in the study will not affect any care you are receiving or will receive in the future.

**What happens when the research study ends?**

Anonymised data will be used as part of a PhD thesis. The findings of the study will be submitted for publication in academic and professional journals and might be presented at local meetings for healthcare professionals and at academic conferences. Some parts of the interview might be directly quoted in publications, but these will be anonymous. You can also have a summary of the findings, if you would like to know the results.

**Who has reviewed this study?**

This study has been reviewed by the academic supervisors of the study, the Research Governance of Swansea University and it has received a favourable opinion from London – South East Research Ethics Committee.

This study has also received an approval from the Research and Development department of



**What if I have a complaint?**

If you have any complaints about the study, please contact Research Governance at Cardiff University on the details stated at the end of this information sheet.

Thank you very much for considering taking part in this study.

IRAS: 17/LO/2123 - 236999 – REEACaRS - PIS – Phase 2 – v 8 – 15.02.2019





For further information, please contact:

Principal investigator/researcher:

Miss Judit Katalin Csontos (Msc, Bsc PT)

PhD Student, School of Healthcare Sciences, Cardiff University

Eastgate House, 35-43 Newport Road, Cardiff University, Cardiff  
CF24 0AB

24 hour answer phone:  E-mail: [CsontosJK@cardiff.ac.uk](mailto:CsontosJK@cardiff.ac.uk)

Academic supervisors:

Dr Tessa Watts (PhD, Msc, Bsc, RN)

Senior Lecturer, School of Healthcare Sciences, Cardiff University  
Eastgate House, 35-43 Newport Road, Cardiff University, Cardiff  
CF24 0AB

E-mail: [wattst1@cardiff.ac.uk](mailto:wattst1@cardiff.ac.uk)

Dr Dominic Roche (PhD, BSc, RN)

Lecturer: Adult Nursing, School of Healthcare Sciences, Cardiff University  
Ty Dewi Sant, Heath Campus, Cardiff  
CF14 4XN

24 hour answer phone: +44(0)2920687801 E-mail: [roched1@cardiff.ac.uk](mailto:roched1@cardiff.ac.uk)

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E-mail: [resgov@cardiff.ac.uk](mailto:resgov@cardiff.ac.uk)

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## Appendix 17: Participant consent form



### Participant Consent Form

**Study Title: Realist evaluation and economic analysis of cancer rehabilitation services in South Wales (REEACaRS)**

Phase 2: face to face, individual, audio recorded interview

Principal Investigator: Judit Katalin Csontos

Participant Identification Number: \_\_\_\_\_

Please read the statements carefully and initial the ones you consent to.

	Please initial the boxes to indicate consent
I confirm that I have read and understood the <b>Participant Information Sheet dated (version)</b> for the above project. I have had the opportunity to consider the information stated in the Participant Information Sheet, ask questions and I have had these answered satisfyingly.	
I understand that my participation is entirely voluntary and that I am free to withdraw from the study at any time without giving any further explanation. I understand that my withdrawal will not affect any care that I receive.	
I agree to take part in a face to face, individual, audio recorded interview for the above study.	
I understand that the information collected during the course of the audio recorded interview will be confidential and anonymised.	
I understand that information from the audio recorded interview will be transcribed (typed up) and anonymised by the researcher. I give permission for the researcher to have access to this information.	
I understand that this anonymised transcript will be read and analysed by the researcher and a second reviewer. I give permission for the researcher and the second reviewer to analyse this data.	
I understand that the researcher will access <b>my hospital notes</b> taken as part of routine assessment of my health during rehabilitation. I give permission to the researcher to access this information.	

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	<b>Please initial the boxes to indicate consent</b>
I agree to the findings of the analysis (including anonymised quotes) being used in the PhD Thesis and for publication in any peer-reviewed academic and professional journals and for presentations at conferences.	
I agree to be re-contacted by the researcher with a summary of the findings of this study.	





**Name of Participant:** \_\_\_\_\_

**Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

Name of Researcher	Date (dd/mm/yyyy)	Signature

## Appendix 18: Companion information sheet

			
<b>Companion Information Sheet</b>			
<b>Study Title: Realist evaluation and economic analysis of cancer rehabilitation services in South Wales (REEACaRS)</b>			
Phase 2: face to face, individual, audio recorded interview			
Principal Investigator: Judit Katalin Csontos			
<p>May I introduce myself? I am Judit Katalin Csontos a Postgraduate Research Student at Cardiff University and my interest is in cancer rehabilitation. At the moment I am looking at how cancer rehabilitation services work in South Wales. As you are supporting a person who has agreed to be interviewed, I would be grateful if you would read this information sheet. If you have any questions or concerns about taking part in this project, you can talk to me, Judit Katalin Csontos, or contact my academic supervisors, Dr Tessa Watts or Dr Dominic Roche directly. Our contact details can be found at the end of this information sheet.</p>			
<p><b>What is the purpose of the study?</b></p> <p>The purpose of this study is to look at how cancer rehabilitation services work in South Wales. Cancer rehabilitation helps with the side effects of cancer and its treatment with the involvement of different healthcare professionals. In South Wales cancer rehabilitation has not been thoroughly investigated. To provide high quality care for everyone it is important to know how services work. In this part of the study (Phase 2) participants will be encouraged to tell their story and experiences about cancer rehabilitation in the form of a face to face, audio recorded interview.</p>			
<p><b>Who is organising and funding the study?</b></p> <p>The project is funded by Macmillan Cancer Support, Swansea University and Cardiff University.</p>			
<p><b>Why have I been asked to read this information sheet?</b></p> <p>You have been asked, because the person, you are supporting, have decided to take part in this study.</p>			
<p><u>IRAS: 17/LO/2123 - 236999 – REEACaRS - Companion Information Sheet – v 8 – 15.02.2019</u></p>			
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**Do I have to take part?**

No, you do not have to take part. Participation in the study is entirely voluntary. However, the research participant you are supporting may wish to involve you or you may like to add your thoughts during the interview. It is up to you to decide if you would like to participate or not. Whatever your decision is, this will not affect you in any way. If there is any information that is not clear, please ask me directly.

**What will happen if I decide to take part?**

After reading this information sheet, if you decide to take part, you will be asked to sign a written consent form and you can ask any questions related to the study from me before signing it. The interview will take a maximum of 60 minutes during a working day. With the research participant's (your partner or friend) permission interviews will be voice recorded and typed up. Your participation is confidential, so I will ensure that any identifying information, including your name, is removed from the typed up notes.

**What are the potential disadvantages of participation in the study?**

Questions will be asked about the research participant's illness, which she/he may find upsetting. If the research participant gets upset at any point during the interviews, you can stop. You might need to comfort her/him. I can also provide support for you and I can give you advice on who to contact with any problems. If the research participant needs any longer term care or support, I can give you the contact details of your healthcare team or other support services.

**What are the potential advantages of participation in the study?**

This study might not benefit you directly, although talking about cancer rehabilitation can help to understand how services work in South Wales. If the operation of services is better understood, it can give information on how to improve cancer rehabilitation and provide the highest quality care.

**Will my participation be kept confidential?**

Yes, it will. Ethical and legal practices will be followed to ensure confidentiality. All identifiable names and information will be removed and participant identifier numbers will be used instead. All data, voice recordings, typed up notes will be kept on a password secured personal computer drive at School of Healthcare Sciences, Cardiff University. All the paper copies of the typed up notes will

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be kept in a lockable filing cabinet with sole access to the researcher at the School of Healthcare Sciences, Cardiff University. All voice recordings and typed up notes will be stored for 15 years from the data collection at Cardiff University. After 15 years all data will be destroyed.

During the interview if any practice that puts patients at risk is reported, I have the professional obligation to bring this to the attention of the gatekeepers of the study sites. If this happens, data will not be included in the research.

**Who will be informed of my participation?**

Your participation is confidential. Apart from the researcher and the research participant, no one will know about your partaking.

**What happens when the research study ends?**

Anonymised data will be used as part of a PhD thesis. The findings of the study will be submitted for publication in academic and professional journals and might be presented at local meetings for healthcare professionals and at academic conferences. Some parts of the interview might be directly quoted in publications, but these will be anonymous. You can also have a summary of the findings, if you would like to know the results.

**Who has reviewed this study?**

This study has been reviewed by the academic supervisors of the study, the Research Governance of Swansea University and it has received a favourable opinion from London – South East Research Ethics Committee.

This study has also received an approval from the Research and Development department of



**What if I have a complaint?**

If you have any complaints about the study, please contact Research Governance at Cardiff University on the details stated at the end of this information sheet.

Thank you very much for considering taking part in this study.

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For further information, please contact:

Principal investigator/researcher:

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CF24 0AB

24 hour answer phone:  E-mail: [CsontosJK@cardiff.ac.uk](mailto:CsontosJK@cardiff.ac.uk)

Academic supervisors:

**Dr Tessa Watts (PhD, Msc, Bsc, RN)**

Senior Lecturer, School of Healthcare Sciences, Cardiff University

Eastgate House, 35-43 Newport Road, Cardiff University, Cardiff  
CF24 0AB

E-mail: [wattst1@cardiff.ac.uk](mailto:wattst1@cardiff.ac.uk)

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Lecturer: Adult Nursing, School of Healthcare Sciences, Cardiff University

Ty Dewi Sant, Heath Campus, Cardiff  
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## Appendix 19: Companion consent form





**Companion Consent Form**

**Study Title: Realist evaluation and economic analysis of cancer rehabilitation services in South Wales (REEACaRS)**

Phase 2: face to face, individual, audio recorded interview

Principal Investigator: Judit Katalin Csontos

Participant Identification Number: \_\_\_\_\_

Please read the statements carefully and initial the ones you consent to.

	Please initial the boxes to indicate consent
I confirm that I have read and understood the <b>Companion Information Sheet</b> dated (version) for the above project. I have had the opportunity to consider the information stated in the Participant Information Sheet, ask questions and I have had these answered satisfyingly.	
I understand that my participation is entirely voluntary and that I am free to withdraw from the study at any time without giving any further explanation. I understand that my withdrawal will not affect any care that I receive.	
I agree to take part in a face to face, individual, audio recorded interview for the above study.	
I understand that the information collected during the course of the audio recorded interview will be confidential and anonymised.	
I understand that information from the audio recorded interview will be transcribed (typed up) and anonymised by the researcher. I give permission for the researcher to have access to this information.	
I understand that this anonymised transcript will be read and analysed by the researcher and a second reviewer. I give permission for the researcher and the second reviewer to analyse this data.	
I agree to the findings of the analysis (including anonymised quotes) being used in the PhD Thesis and for publication in any peer-reviewed academic and professional journals and for presentations at conferences.	

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**Name of Companion:** \_\_\_\_\_

**Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

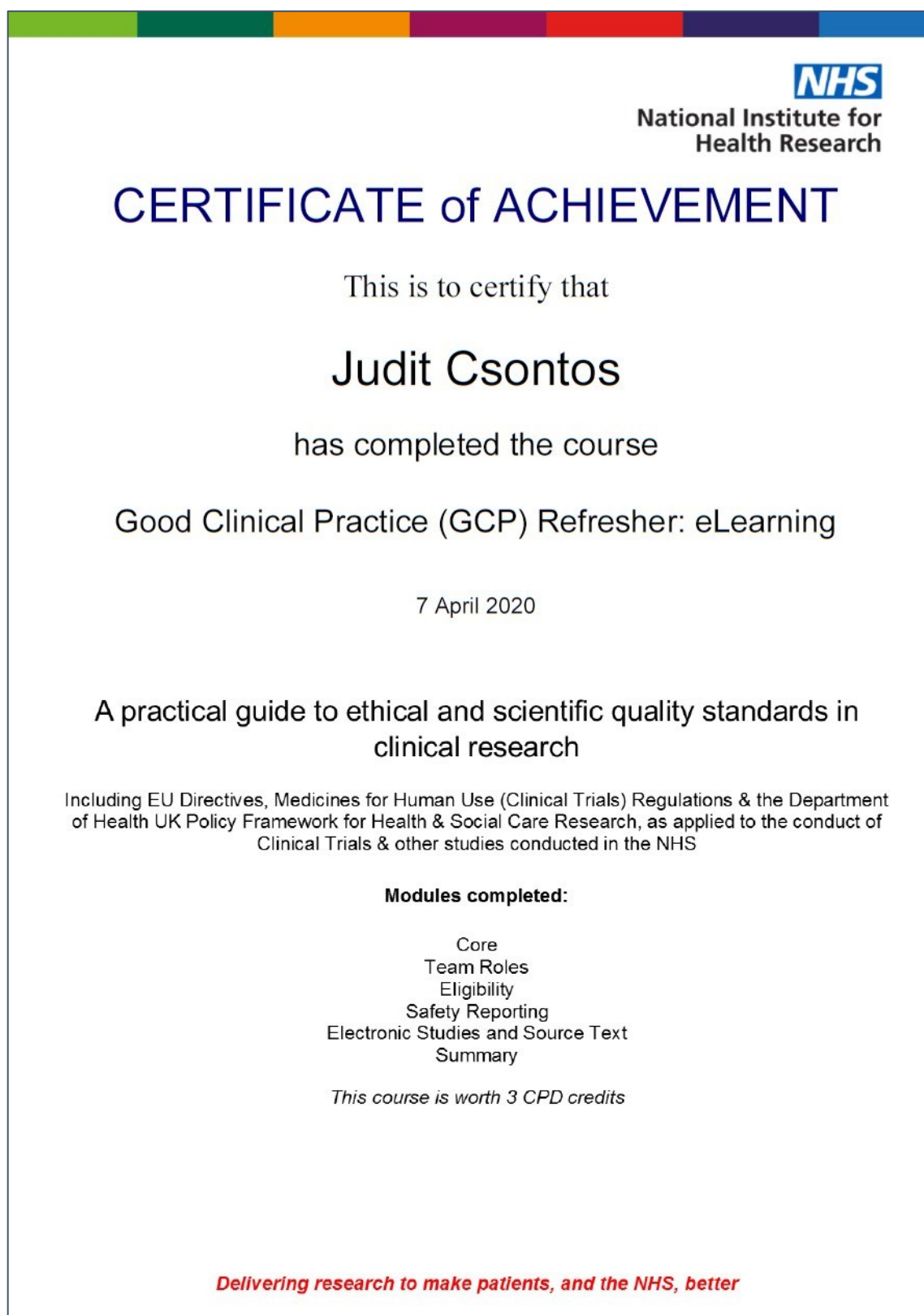
Name of Researcher	Date (dd/mm/yyyy)	Signature

IRAS: 17/LO/2123 - 236999 – REEACaRS - Companion Consent Form – v 6 – 14.02.2019



## Appendix 20: Good Clinical Practice introductory certificate

 <p>Ymchwil Iechyd a Gofal Cymru Health and Care Research Wales</p>	 <p>Ariennir gan Lywodraeth Cymru Funded by Welsh Government</p>			
 <p>NIHR CRN Workforce Development <i>Enabling learning and development in the Clinical Research Network</i></p>	 <p><b>National Institute for Health Research</b></p>			
<h3>Certificate of Attendance</h3> <p>Judit Katalin Csontos</p> <p>attended</p> <p><b>Introduction to Good Clinical Practice (GCP):</b> A practical guide to ethical and scientific quality standards in clinical research</p> <p>on 7<sup>th</sup> August, 2017</p> <p>Sessions include:</p> <ol style="list-style-type: none"><li>1. The Value of Clinical Research and the role of NIHR CRN &amp; Health and Care Research Wales</li><li>2. Introduction to research and the GCP standards</li><li>3. Preparing to deliver your study</li><li>4. Identifying and recruiting participants: Eligibility &amp; Informed Consent</li><li>5. Data collection and ongoing study delivery</li><li>6. Safety reporting and Study closure</li></ol> <p>Including EU Directives, Medicines for Human Use (Clinical Trials) Regulations and the Department of Health Research Governance Framework for Health and Social Care, as applied to the conduct of Clinical Trials and other studies conducted in the NHS</p> <p><b>This course is accredited by the CPD Certification Service (6.5 Hours) and the Royal College of Physicians (6 CPD points) CPD Code: 114222</b></p> <table><tr><td><p>CPD MEMBER The CPD Certification Service</p></td><td><p>Senior Training &amp; Development Manager Health and Care Research Wales Support Centre</p></td><td><p>NIHR CRN Learning &amp; Development Lead</p></td></tr></table>		 <p>CPD MEMBER The CPD Certification Service</p>	 <p>Senior Training &amp; Development Manager Health and Care Research Wales Support Centre</p>	 <p>NIHR CRN Learning &amp; Development Lead</p>
 <p>CPD MEMBER The CPD Certification Service</p>	 <p>Senior Training &amp; Development Manager Health and Care Research Wales Support Centre</p>	 <p>NIHR CRN Learning &amp; Development Lead</p>		



## Appendix 22: Interview length

Site	Participant	Profession/cancer type	Interview Length
Willow	Participant_01	Prostate	1:02:21
Willow	Participant_02	Colorectal	1:31:21
Willow	Participant_03	Breast	0:55:43
Willow	Participant_09	Prostate	1:25:05
Willow	Participant_10	Prostate	1:04:21
Willow	Participant_12	Prostate	1:01:59
Willow	Participant_16	Prostate	1:05:51
Willow	Participant_28	Breast	0:49:49
Willow	Participant_30	Prostate	0:28:14
Fern	Participant_18	Breast	0:47:11
Fern	Participant_21	Breast	0:44:45
Fern	Participant_27	Lung	0:38:01
Fern	Participant_29	Prostate	0:55:16
Fern	Participant_37	Breast	0:37:22
Fern	Participant_39	Thyroid	0:42:48
Willow	Professional_01	Occupational therapist	0:48:23
Willow	Professional_10	Technician	0:43:30
Willow	Professional_11	Speech and language therapist	1:10:16
Willow	Professional_14	Occupational therapist	1:34:23
Willow	Professional_15	Physiotherapist	0:51:47
Willow	Professional_16	Occupational therapist	0:32:54
Willow	Professional_17	Dietitian	1:36:21
Willow	Professional_18	Dietitian	1:30:05
Willow	Professional_19	Physiotherapist	0:54:54
Willow	Professional_20	Occupational therapist	0:57:17
Fern	Professional_02	Speech and language therapist	0:51:45
Fern	Professional_03	Technician	0:33:43
Fern	Professional_04	Dietitian	0:42:52
Fern	Professional_05	Technician	0:26:12
Fern	Professional_06	Physiotherapist	0:35:13
Fern	Professional_07	Dietitian	0:43:06
Fern	Professional_08	Technician	0:57:41
Fern	Professional_09	Speech and language therapist	1:09:28
Fern	Professional_12	Occupational therapist	1:18:11
Fern	Professional_13	Speech and language therapist	1:17:56
Total length:			33:06:04

## Appendix 23: Available data percentage for secondary analysis

Available data percentage in 2014					
Episode number	FACIT-F	TUAG	QOL	PAIN	SOB
0	3.80%	3.80%	3.80%	0.00%	1.90%
1	33.50%	47.60%	52.40%	19.50%	4.90%
2	53.10%	83.70%	81.60%	26.50%	0.00%
3	53.30%	93.30%	93.30%	26.70%	0.00%
4	32.00%	88.00%	88.00%	24.00%	4.00%
5	41.20%	82.40%	76.50%	47.10%	0.00%
6	57.10%	100.00%	100.00%	71.40%	0.00%
7	60.00%	100.00%	100.00%	80.00%	0.00%
8	25.00%	100.00%	100.00%	100.00%	0.00%
9	50.00%	100.00%	100.00%	100.00%	0.00%
10	0.00%	100.00%	100.00%	100.00%	0.00%

Available data percentage in 2015					
Episode number	FACIT-F	TUAG	QOL	PAIN	SOB
0	1.50%	0.00%	1.50%	0.00%	0.00%
1	36.10%	40.00%	45.00%	30.70%	20.40%
2	45.30%	53.50%	58.10%	36.00%	17.40%
3	55.80%	67.40%	69.80%	46.50%	14.00%
4	36.80%	31.60%	47.40%	47.40%	5.30%
5	33.30%	44.40%	55.60%	44.40%	11.10%
6	37.50%	37.50%	37.50%	25.00%	0.00%
7	20.00%	0.00%	20.00%	20.00%	0.00%
8	66.70%	66.70%	66.70%	66.70%	0.00%
9	100.00%	100.00%	100.00%	100.00%	0.00%
10	0.00%	0.00%	0.00%	0.00%	0.00%



Available data percentage in 2016					
Episode number	FACIT-F	TUAG	QOL	PAIN	SOB
0	20.00%	0.00%	20.00%	0.00%	0.00%
1	25.70%	25.30%	28.80%	25.70%	20.90%
2	31.00%	25.90%	36.20%	34.50%	25.90%
3	45.50%	36.40%	50.00%	59.10%	59.10%
4	53.80%	46.20%	53.80%	53.80%	53.80%
5	71.40%	57.10%	71.40%	57.10%	28.60%
6	66.70%	66.70%	66.70%	50.00%	16.70%
7	75.00%	50.00%	75.00%	50.00%	50.00%
8	75.00%	25.00%	50.00%	75.00%	25.00%
9	50.00%	0.00%	0.00%	50.00%	50.00%
Unknown	0.00%	0.00%	0.00%	0.00%	0.00%

Available data percentage in 2017					
Episode number	FACIT-F	TUAG	QOL	PAIN	SOB
1	26.40%	18.90%	29.20%	26.40%	15.60%
2	54.80%	40.30%	56.50%	41.90%	25.80%
3	40.60%	43.80%	50.00%	43.80%	25.00%
4	35.30%	23.50%	35.30%	29.40%	29.40%
5	62.50%	37.50%	62.50%	62.50%	50.00%
6	25.00%	50.00%	50.00%	50.00%	25.00%
7	50.00%	0.00%	50.00%	50.00%	50.00%
8	100.00%	0.00%	100.00%	100.00%	100.00%
9	100.00%	50.00%	100.00%	100.00%	50.00%
10	100.00%	50.00%	100.00%	100.00%	50.00%
11	100.00%	100.00%	100.00%	100.00%	100.00%
12	0.00%	0.00%	0.00%	0.00%	0.00%
Unknown	0.00%	0.00%	0.00%	0.00%	0.00%

## Appendix 24: Willow Therapy Team staff numbers from 2014 to 2017

Outpatients					
2014	Grade 8a	Grade 7	Grade 6	Grade 5	Grade 3
OT		37.5 hours			
PT				30 hours	30 hours
2015	Grade 8a	Grade 7	Grade 6	Grade 5	Grade 3
OT		37.5 hours	*37.5 hours		
PT				15 hours	***22.5 hours
2016	Grade 8a	Grade 7	Grade 6	Grade 5	Grade 3
OT		22.5 hours	^37.5 hours	**30 hours	
PT	18.75 hours				30 hours
2017	Grade 8a	Grade 7	Grade 6	Grade 5	Grade 3
OT			37.5 hours	30 hours	15 hours
PT				^^37.5 hours	***30 hours

Key: OT - occupational therapist; PT - physiotherapist; \* only started in September 2015; \*\* only started in April 2016; \*\*\* contract ended in July; ^ On maternity leave from June 2016; ^^ On maternity leave from March 2017

## Appendix 25: Mean and median outcome measure scores in 2014

Episode number	FACIT-F 2014							
	PRE Exercise class				POST Exercise class			
	n	Mean	SD	Median	n	Mean	SD	Median
0	2	36.500	10.607	36.500	2	25.750	16.617	25.750
1	55	25.642	10.793	24.000	55	30.732	11.776	31.000
2	26	26.385	10.092	25.000	26	32.106	11.197	33.500
3	16	28.125	11.430	29.000	16	30.047	11.869	31.000
4	8	27.969	14.158	29.000	8	27.250	14.300	21.500
5	7	26.179	14.743	29.000	7	26.714	16.604	22.000
6	4	22.000	8.042	24.500	4	20.500	11.705	23.000
7	3	19.000	12.124	21.000	3	20.000	15.395	16.000
8	1	Cannot be computed			1	Cannot be computed		
9	1	Cannot be computed			1	Cannot be computed		
10	No valid cases				No valid cases			

Episode number	TUAG 2014							
	PRE Exercise class				POST Exercise class			
	n	Mean	SD	Median	n	Mean	SD	Median
0	2	6.510	0.141	6.510	2	7.375	2.920	7.375
1	78	9.144	4.254	7.610	78	8.142	3.541	6.915
2	41	8.615	3.733	7.760	41	7.845	3.737	6.750
3	28	8.481	3.820	7.165	28	8.404	4.175	6.965
4	22	10.640	12.380	7.575	22	10.078	10.257	7.635
5	14	14.614	15.028	10.155	14	14.262	12.687	9.775
6	7	18.479	15.751	12.580	7	20.240	19.436	14.370
7	5	24.164	22.199	15.280	5	25.365	25.283	14.970
8	4	42.895	26.304	43.835	4	40.840	24.567	39.880
9	2	20.635	8.012	20.635	2	20.360	8.443	20.360
10	1	Cannot be computed			1	Cannot be computed		

Episode number	QOL 2014							
	PRE Exercise class				POST Exercise class			
	n	Mean	SD	Median	n	Mean	SD	Median
0	2	85.000	21.213	85.000	2	45.000	21.213	45.000
1	86	58.709	17.845	60.000	86	70.029	16.353	70.000
2	40	62.813	15.985	65.000	40	69.025	14.407	70.000
3	28	59.464	21.617	57.500	28	65.821	19.013	70.000
4	22	58.659	27.059	67.500	22	60.000	25.402	60.000
5	13	54.615	25.369	55.000	13	53.462	28.823	50.000
6	7	41.429	22.493	40.000	7	39.286	26.209	40.000
7	5	43.000	24.900	50.000	5	32.000	31.145	30.000
8	4	21.250	21.747	17.500	4	12.500	12.583	10.000
9	2	20.000	14.142	20.000	2	50.000	28.284	50.000
10	1	Cannot be computed			1	Cannot be computed		

Episode number	PAIN 2014							
	PRE Exercise class				POST Exercise class			
	n	Mean	SD	Median	n	Mean	SD	Median
0	No valid cases				No valid cases			
1	32	5.891	2.368	6.250	32	3.430	2.504	3.500
2	13	5.615	2.623	5.000	13	4.539	2.286	5.000
3	8	6.438	2.008	6.250	8	5.531	1.650	5.000
4	6	7.000	2.214	7.250	6	6.250	2.230	6.500
5	8	7.375	2.387	8.250	8	7.000	2.375	7.750
6	5	7.700	1.718	8.500	5	7.900	1.817	8.500
7	4	8.625	1.250	8.750	4	8.125	2.175	8.250
8	4	9.375	0.750	9.500	4	7.875	2.529	8.250
9	2	8.250	2.475	8.250	2	9.000	1.414	9.000
10	1	Cannot be computed			1	Cannot be computed		

Episode number	SOB 2014							
	PRE Exercise class				POST Exercise class			
	n	Mean	SD	Median	n	Mean	SD	Median
0	1	Cannot be computed			1	Cannot be computed		
1	8	4.625	1.620	4.250	8	4.250	2.236	4.500
2	No valid cases				No valid cases			
3	No valid cases				No valid cases			
4	1	Cannot be computed			1	Cannot be computed		
5	No valid cases				No valid cases			
6	No valid cases				No valid cases			
7	No valid cases				No valid cases			
8	No valid cases				No valid cases			
9	No valid cases				No valid cases			
10	No valid cases				No valid cases			

## Appendix 26: Mean and median outcome measure scores in 2015

Episode number	FACIT-F 2015							
	PRE Exercise class				POST Exercise class			
	n	Mean	SD	Median	n	Mean	SD	Median
0	1	Cannot be computed			1	Cannot be computed		
1	101	26.931	9.880	27.000	101	30.842	10.820	30.000
2	39	32.590	10.745	35.000	39	32.539	10.321	33.000
3	24	29.996	10.244	29.500	24	29.833	11.427	31.000
4	7	19.571	10.983	17.000	7	19.429	6.425	21.000
5	3	24.000	2.646	23.000	3	23.667	5.132	25.000
6	3	26.333	11.150	22.000	3	27.333	14.189	30.000
7	1	Cannot be computed			1	Cannot be computed		
8	2	18.000	0.000	18.000	2	19.000	0.000	19.000
9	3	17.667	1.528	18.000	3	13.667	4.509	14.000
10	No valid cases				No valid cases			

Episode number	TUAG 2015							
	PRE Exercise class				POST Exercise class			
	n	Mean	SD	Median	n	Mean	SD	Median
0	No valid cases				No valid cases			
1	112	10.226	4.764	9.080	112	9.069	6.223	7.720
2	46	10.191	8.719	8.040	46	8.892	5.000	7.420
3	29	10.437	5.497	7.770	29	9.406	4.778	6.970
4	6	11.218	4.278	11.395	6	10.875	4.892	10.490
5	4	10.723	5.104	12.085	4	7.895	3.084	8.830
6	3	13.253	8.651	10.320	3	13.310	9.293	10.110
7	No valid cases				No valid cases			
8	2	14.390	0.000	14.390	2	13.050	0.000	13.050
9	3	17.810	7.395	14.050	3	17.187	6.792	14.050
10	No valid cases				No valid cases			

Episode number	QOL 2015							
	PRE Exercise class				POST Exercise class			
	n	Mean	SD	Median	n	Mean	SD	Median
0	1	Cannot be computed			1	Cannot be computed		
1	126	58.246	18.734	60.000	126	65.659	16.947	70.000
2	50	64.260	17.100	60.000	50	64.700	16.168	64.000
3	30	59.533	12.555	60.000	30	62.167	15.630	60.000
4	9	57.222	23.994	60.000	9	66.778	18.192	70.000
5	5	51.000	22.472	50.000	5	59.000	8.944	60.000
6	3	70.000	17.321	80.000	3	63.333	15.275	60.000
7	1	Cannot be computed			1	Cannot be computed		
8	2	30.000	0.000	30.000	2	30.000	0.000	30.000
9	3	40.000	26.458	30.000	3	36.667	28.868	20.000
10	No valid cases				No valid cases			

Episode number	PAIN 2015							
	PRE Exercise class				POST Exercise class			
	n	Mean	SD	Median	n	Mean	SD	Median
0	No valid cases				No valid cases			
1	86	5.218	2.240	5.000	86	4.233	2.302	4.000
2	31	4.839	2.142	5.000	31	4.436	2.171	5.000
3	20	5.025	1.923	5.000	20	4.763	2.022	5.000
4	9	5.972	1.679	6.000	9	5.111	2.369	6.000
5	4	4.625	1.250	4.750	4	4.188	0.944	4.250
6	2	2.875	0.530	2.875	2	5.000	0.707	5.000
7	1	Cannot be computed			1	Cannot be computed		
8	2	8.000	0.000	8.000	2	7.250	0.000	7.250
9	3	8.667	1.377	8.750	3	8.417	1.774	8.750
10	No valid cases				No valid cases			

Episode number	SOB 2015							
	PRE Exercise class				POST Exercise class			
	n	Mean	SD	Median	n	Mean	SD	Median
0	No valid cases				No valid cases			
1	57	4.298	2.279	4.000	57	3.904	2.235	4.000
2	15	4.867	2.709	5.000	15	3.467	2.869	3.000
3	6	3.333	2.183	3.750	6	2.833	1.915	3.500
4	1	Cannot be computed			1	Cannot be computed		
5	1	Cannot be computed			1	Cannot be computed		
6	No valid cases				No valid cases			
7	No valid cases				No valid cases			
8	No valid cases				No valid cases			
9	No valid cases				No valid cases			
10	No valid cases				No valid cases			



## Appendix 27: Mean and median outcome measure scores in 2016

Episode number	FACIT-F 2016							
	PRE Exercise class				POST Exercise class			
	n	Mean	SD	Median	n	Mean	SD	Median
0	1	Cannot be computed			1	Cannot be computed		
1	75	24.785	10.559	25.000	75	30.322	10.836	30.000
2	18	27.444	9.787	28.000	18	26.583	10.143	25.500
3	10	30.600	11.187	29.500	10	33.200	12.291	32.000
4	7	30.857	15.593	31.000	7	28.571	17.971	19.000
5	5	18.636	12.385	14.180	5	23.200	11.946	16.000
6	4	18.250	7.136	17.000	4	14.250	3.862	14.500
7	3	13.000	3.606	12.000	3	15.333	6.429	18.000
8	3	17.000	8.544	18.000	3	14.333	5.033	15.000
9	1	Cannot be computed			1	Cannot be computed		
Unknown	No valid cases				No valid cases			

Episode number	TUAG 2016							
	PRE Exercise class				POST Exercise class			
	n	Mean	SD	Median	n	Mean	SD	Median
0	No valid cases				No valid cases			
1	74	9.689	5.789	8.075	74	8.864	4.785	7.660
2	15	10.794	8.056	8.000	15	9.417	7.273	6.420
3	8	8.119	2.646	6.765	8	7.801	3.526	6.750
4	6	9.620	5.528	7.345	6	9.168	5.232	6.610
5	4	12.973	5.305	14.575	4	12.658	5.189	13.830
6	4	10.503	3.577	11.430	4	11.390	4.916	12.490
7	2	9.890	6.972	9.890	2	10.425	7.432	10.425
8	1	Cannot be computed			1	Cannot be computed		
9	No valid cases				No valid cases			
Unknown	No valid cases				No valid cases			

Episode number	QOL 2016							
	PRE Exercise class				POST Exercise class			
	n	Mean	SD	Median	n	Mean	SD	Median
0	1	Cannot be computed			1	Cannot be computed		
1	84	61.619	18.852	65.000	84	69.321	18.364	70.000
2	21	62.619	18.481	60.000	21	65.952	14.800	70.000
3	11	64.091	20.955	70.000	11	65.000	25.690	70.000
4	7	61.429	26.882	65.000	7	60.000	26.458	50.000
5	5	40.000	20.000	30.000	5	54.000	26.077	50.000
6	4	56.500	18.138	63.000	4	52.500	20.616	55.000
7	3	46.667	20.817	40.000	3	39.000	10.149	37.000
8	2	47.500	24.749	47.500	2	47.500	24.749	47.500
9	No valid cases				No valid cases			
Unknown	No valid cases				No valid cases			

Episode number	PAIN 2016							
	PRE Exercise class				POST Exercise class			
	n	Mean	SD	Median	n	Mean	SD	Median
0	No valid cases				No valid cases			
1	75	4.700	2.364	5.000	75	3.788	2.756	4.000
2	20	4.825	2.313	4.500	20	4.875	2.356	5.000
3	13	4.346	2.366	5.000	13	3.731	2.333	3.000
4	7	4.857	1.676	5.000	7	4.714	3.039	6.000
5	4	7.500	0.577	7.500	4	7.875	0.629	8.000
6	3	6.333	2.566	7.000	3	6.000	2.000	6.000
7	2	7.000	1.414	7.000	2	9.000	0.000	9.000
8	3	7.667	2.309	9.000	3	7.667	3.215	9.000
9	1	Cannot be computed			1	Cannot be computed		
Unknown	No valid cases				No valid cases			

Episode number	SOB 2016							
	PRE Exercise class				POST Exercise class			
	n	Mean	SD	Median	n	Mean	SD	Median
0	No valid cases				No valid cases			
1	61	3.369	2.766	3.500	61.000	3.320	2.755	3.000
2	15	2.433	2.744	2.000	15.000	1.967	3.026	0.000
3	13	1.846	2.349	2.000	13.000	3.346	2.968	3.000
4	7	2.429	3.599	1.000	7.000	3.286	3.592	3.000
5	2	8.000	0.000	8.000	2.000	8.000	0.000	8.000
6	1	Cannot be computed			1	Cannot be computed		
7	2	1.500	2.121	1.500	2.000	7.500	0.707	7.500
8	1	Cannot be computed			1	Cannot be computed		
9	1	Cannot be computed			1	Cannot be computed		
Unknown	No valid cases				No valid cases			

## Appendix 28: Mean and median outcome measure scores in 2017

Episode number	FACIT-F 2017							
	PRE Exercise class				POST Exercise class			
	n	Mean	SD	Median	n	Mean	SD	Median
1	56	28.232	11.921	29.500	56	31.214	10.576	31.500
2	34	31.941	10.427	33.500	34	32.147	12.560	36.500
3	13	29.615	11.169	29.000	13	29.154	11.142	32.000
4	6	28.000	12.696	29.500	6	29.000	11.100	33.000
5	5	32.000	13.565	34.000	5	29.200	16.285	31.000
6	1	Cannot be computed			1	Cannot be computed		
7	1	Cannot be computed			1	Cannot be computed		
8	1	Cannot be computed			1	Cannot be computed		
9	2	9.500	7.778	9.500	2	10.000	5.657	10.000
10	2	10.000	5.65685	10.000	2	20.000	7.071	20.000
11	1	Cannot be computed			1	Cannot be computed		
12	No valid cases				No valid cases			
Unknown	No valid cases				No valid cases			



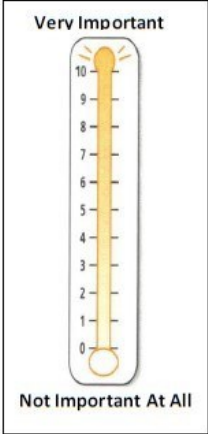
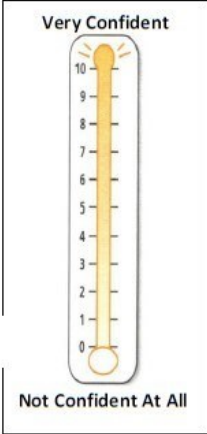
Episode number	TUAG 2017							
	PRE Exercise class				POST Exercise class			
	n	Mean	SD	Median	n	Mean	SD	Median
1	40	8.032	2.914	7.445	40	6.918	2.253	6.325
2	25	8.090	3.028	7.500	25	7.391	2.745	6.700
3	14	7.719	2.791	6.700	14	7.029	2.228	6.655
4	4	6.980	2.171	7.510	4	6.813	1.639	7.400
5	3	9.400	4.197	7.700	3	7.940	3.033	6.540
6	2	6.200	0.481	6.200	2	5.960	0.863	5.960
7	No valid cases				No valid cases			
8	No valid cases				No valid cases			
9	1	Cannot be computed			1	Cannot be computed		
10	1	Cannot be computed			1	Cannot be computed		
11	1	Cannot be computed			1	Cannot be computed		
12	No valid cases				No valid cases			
Unknown	No valid cases				No valid cases			

Episode number	QOL 2017							
	PRE Exercise class				POST Exercise class			
	n	Mean	SD	Median	n	Mean	SD	Median
1	62	62.581	18.438	67.500	62	66.936	18.093	70.000
2	35	67.000	18.117	70.000	35	68.286	16.845	70.000
3	16	69.688	13.961	70.000	16	69.688	22.171	70.000
4	6	69.167	17.440	70.000	6	63.333	21.602	65.000
5	5	60.000	22.361	60.000	5	53.000	23.875	50.000
6	2	77.500	3.536	77.500	2	77.500	10.607	77.500
7	1	Cannot be computed			1	Cannot be computed		
8	1	Cannot be computed			1	Cannot be computed		
9	2	30.000	0.000	30.000	2	45.000	7.071	45.000
10	2	45.000	7.071	45.000	2	35.000	35.355	35.000
11	1	Cannot be computed			1	Cannot be computed		
12	No valid cases				No valid cases			
Unknown	No valid cases				No valid cases			

Episode number	PAIN 2017							
	PRE Exercise class				POST Exercise class			
	n	Mean	SD	Median	n	Mean	SD	Median
1	56	5.7411	3.126	6.000	56	4.696	3.042	4.000
2	26	5.519	3.315	5.000	26	5.442	2.677	5.500
3	14	4.893	2.588	4.500	14	5.429	2.441	5.000
4	5	4.900	2.559	5.000	5	7.600	2.074	8.000
5	5	7.000	2.000	8.000	5	5.100	2.510	5.000
6	2	5.500	4.950	5.500	2	3.750	2.475	3.750
7	1	Cannot be computed			1	Cannot be computed		
8	1	Cannot be computed			1	Cannot be computed		
9	2	8.000	1.414	8.000	2	6.500	2.121	6.500
10	2	6.500	2.121	6.500	2	4.500	6.364	4.500
11	1	Cannot be computed			1	Cannot be computed		
12	No valid cases				No valid cases			
Unknown	No valid cases				No valid cases			

Episode number	SOB 2017							
	PRE Exercise class				POST Exercise class			
	n	Mean	SD	Median	n	Mean	SD	Median
1	33	3.470	2.718	3.000	33.000	2.773	2.088	2.000
2	16	3.688	2.555	3.250	16.000	4.000	2.280	4.000
3	8	2.375	2.066	2.500	8.000	2.250	1.282	2.500
4	5	3.100	2.966	2.500	5.000	3.800	2.168	3.000
5	4	3.250	3.403	2.500	4.000	5.375	3.092	5.750
6	1	Cannot be computed			1	Cannot be computed		
7	1	Cannot be computed			1	Cannot be computed		
8	1	Cannot be computed			1	Cannot be computed		
9	1	Cannot be computed			1	Cannot be computed		
10	1	Cannot be computed			1	Cannot be computed		
11	1	Cannot be computed			1	Cannot be computed		
12	No valid cases				No valid cases			
Unknown	No valid cases				No valid cases			

## Appendix 29: Modified concerns checklist

 			<div style="text-align: center;"> <h3>Health &amp; Wellbeing Needs Assessment</h3> </div> <div style="border: 1px solid black; padding: 5px; margin-top: 10px;"> PATIENT NAME:   HOSPITAL NUMBER:   DATE OF BIRTH: </div>		
<p>We would like to know how you are feeling and if we can help you with any concerns caused by your cancer or cancer treatment. Please tick your <b>three</b> priorities from the list below.</p> <table style="width: 100%; border: none;"> <tr> <td style="width: 50%; vertical-align: top;"> <input type="checkbox"/> Discomfort / Pain  <input type="checkbox"/> Pins &amp; Needles / Numbness  <input type="checkbox"/> Breathlessness  <input type="checkbox"/> Tiredness / Fatigue / Sleep Disturbance  <input type="checkbox"/> Washing and/or Dressing  <input type="checkbox"/> Walking  <input type="checkbox"/> Sexual function  <input type="checkbox"/> Concentration / Memory  <input type="checkbox"/> Difficulty speaking / hearing / seeing </td> <td style="width: 50%; vertical-align: top;"> <input type="checkbox"/> Home Environment  <input type="checkbox"/> Finances / Money  <input type="checkbox"/> Work / Study  <input type="checkbox"/> Low mood / Depression  <input type="checkbox"/> Worry / Anxiety  <input type="checkbox"/> Loss of interest in usual activities  <input type="checkbox"/> Relationship with family and / or friends  <input type="checkbox"/> Need for information  <input type="checkbox"/> Weight management </td> </tr> </table>				<input type="checkbox"/> Discomfort / Pain <input type="checkbox"/> Pins & Needles / Numbness <input type="checkbox"/> Breathlessness <input type="checkbox"/> Tiredness / Fatigue / Sleep Disturbance <input type="checkbox"/> Washing and/or Dressing <input type="checkbox"/> Walking <input type="checkbox"/> Sexual function <input type="checkbox"/> Concentration / Memory <input type="checkbox"/> Difficulty speaking / hearing / seeing	<input type="checkbox"/> Home Environment <input type="checkbox"/> Finances / Money <input type="checkbox"/> Work / Study <input type="checkbox"/> Low mood / Depression <input type="checkbox"/> Worry / Anxiety <input type="checkbox"/> Loss of interest in usual activities <input type="checkbox"/> Relationship with family and / or friends <input type="checkbox"/> Need for information <input type="checkbox"/> Weight management
<input type="checkbox"/> Discomfort / Pain <input type="checkbox"/> Pins & Needles / Numbness <input type="checkbox"/> Breathlessness <input type="checkbox"/> Tiredness / Fatigue / Sleep Disturbance <input type="checkbox"/> Washing and/or Dressing <input type="checkbox"/> Walking <input type="checkbox"/> Sexual function <input type="checkbox"/> Concentration / Memory <input type="checkbox"/> Difficulty speaking / hearing / seeing	<input type="checkbox"/> Home Environment <input type="checkbox"/> Finances / Money <input type="checkbox"/> Work / Study <input type="checkbox"/> Low mood / Depression <input type="checkbox"/> Worry / Anxiety <input type="checkbox"/> Loss of interest in usual activities <input type="checkbox"/> Relationship with family and / or friends <input type="checkbox"/> Need for information <input type="checkbox"/> Weight management				
<p>Please mark on the scale how <b>important</b> it is for you to make a change in these areas of your life.</p> <div style="text-align: center; margin-top: 20px;">  </div>		<p>Please mark on the scale how <b>confident</b> you are to make a change in these areas of your life.</p> <div style="text-align: center; margin-top: 20px;">  </div>			
<p>Would you like the <span style="background-color: black; color: black;">[REDACTED]</span> to assist you in making a change to these areas of your life?  Yes / No</p> <p>Signature: ..... Date: .....</p> <p style="text-align: center;">7</p>					

## Appendix 30: Critical appraisal of review papers

Author	Issues identified on CASP	CASP score
Browall et al. 2018	3. Only English language; no mention of unpublished studies or contact with experts; no mention of follow up from reference list; 4. Clear description of quality assessment process, but no mention or example of the actual biases of the included studies.	8
Clifford et al. 2018	3. Only English language; unpublished studies were not included; no mention of follow up from reference list; 4. Clear description of quality assessment process, but no mention or example of the actual biases of the included studies. 7. Qualitative themes have been insufficiently developed. Main themes are too vague.	7
Fox et al. 2019	3. Only English language; 4. Quality assessment result only mentioned in Appendices	8
Granger et al. 2017	3. Only English language; only peer-reviewed no mention of unpublished studies or contact with experts	9
Lavallée et al. 2019	3. Only English language; only peer-reviewed no mention of unpublished studies or contact with experts; no mention of follow-up from reference lists	9
Livsey and Lewis 2019	3. Only English language; only peer-reviewed no mention of unpublished studies or contact with experts	9
Michael et al. 2020	3. Only English language; only peer-reviewed no mention of unpublished studies or contact with experts; published articles numbers do not add up, different numbers in the results section than presented in the table; no mention of the exact use of search terms; the word combinations, boolean operators or wildcards	9
Midtgaard et al. 2015	3. Only English language; only peer-reviewed no mention of unpublished studies; no mention of exact search terms, not even in the supplementary documents	9
Yannitsos et al. 2020	PRISMA-ScR Checklist for scoping reviews: 5. No registration or protocol mentioned; 8. No detailed description of the search term combinations or limits used; 12. No mention of critical appraisal; 16. No critical appraisal mentioned; 22. No mention of funding sources, but no conflict of interest declared	N/A



## Appendix 31: Critical appraisal of qualitative research papers

Author	Issues identified on CASP	CASP score
Baker et al.	4. recruitment strategy: more medical professionals than allied health; snowball method, although thorough. 5. no mention of who did the transcription; lack of information of the mode of interviews (phone or face-to face; how long they lasted) 6. No relationship between participants and researchers discussed. 7. Ethical issues - verbal consent? 8. lack of methods described, only constant comparing mentioned; lack of limitations mentioned; lack of representativeness in the paper from dietitians	6
Beidas et al.	5. Length of the interviews not mentioned; mode: (phone, face to face), how many of the participants were in focus groups and how many individual? 6. No relationship considered between researcher and participants; 9. descriptive themes, disjointed presentation of themes; more like topics than themes; lack of limitations mentioned	7
Bourke et al.	4. Miscalculated Table 1. Mentioned 37 professional participants, but 38 is in the table. 6. Relationship was not examined between researcher and participants 9. Only bucket themes; no reflexivity; no reliability mentioned; lack of limitations mentioned regarding qualitative research	7
Carter et al.	4. Recruitment strategy not explicitly mentioned; lack of physiotherapist, psychologist, and occupational therapist involvement; 5. Focus group participant could not be identified by profession, which could bias some results as the perspectives and experiences might be unclear	8
Dennett et al.	8. no mention of how transcription was done; no further mention of phenomenological approach 10. small sample of women, not representing men's views	8
Fong et al.	8. No mention on who did the transcription. Lack of mention on how many people took part in the analysis; lack of mention on full trustworthiness procedures; although reflexivity mentioned; using previous literature might have constrained the analysis	9
Granger et al.	4. Only one city in Australia is represented. Lack of nurses recruited, lack of OTs. 8. Unsure whether data was analysed with content or with thematic analysis (content and thematic analysis used interchangeably)	9

Author	Issues identified on CASP	CASP score
Handberg et al.	4. Theoretical sampling mentioned, but unclear how these 3 hospitals were chosen and why those 58 professionals. No oncologist, physiotherapist, or OT representation. It was also unclear what diagnosis male participants who were observed suffered from. Professionals interviewed were almost all female, which could have biased the results. The all male survivor focus did not allow to see if participant attitudes were similar to female participants. 5. Length of focus groups was not mentioned, number of people in one focus group is unknown 8. No mention of who did the transcription.	7
Ijsbrandy et al.	4. Difference in how professionals were approached in different settings, reason for this not explained; unsure how many professionals were contacted and how many agreed to take part; 5. Not sure why PHP were individually interviewed and why SHP were in a focus group; big focus group number -> some professional opinions might have been missed out; hierarchy within the group not considered (which could hinder free speech); 6. No reflexivity; 8. no mention on who transcribed the data; rigour not really mentioned	6
Jakobsson et al.	4. Focus groups were hard to organise, resulting in a small sample; people might have been silenced due to the group norms. 5. No mention of how many people responded and how many took part in the end. 6. No consideration on the relationship between researcher and participants. 7. No mention. 8. No mention on measures to ensure rigour.	5
James-Martin et al.	4. No appropriate description of who took part in each focus groups. We know that patient focus groups were separate, but hierarchy in professional focus group could influence responses. 5. Recruitment only involved eager patients as it was voluntary, and participants signed up only if they were interested. No response rate for staff e-mails mentioned. Numbers regarding participants do not add up. 6. No elaboration on the relationship between researcher and participants, also no mention of how the moderator could have influenced the focus groups. 8. No rigour methods mentioned. Code system was agreed by professionals, but only one of them coded all interviews. 10. small sample size and high heterogeneity of the group can influence the findings	5

Author	Issues identified on CASP	CASP score
Kenyon et al.	4. Recruitment through CSP; it is possible that people not necessarily check these networks even though they treat patients with ULMI; all female participants, which could be a barrier 6. No mention of the relationship between researcher and participants and no mention on who analysed the data. 8. No mention on who transcribed the data	7
McCartney et al.	4. No AHPs recruited. Why the chosen three professional groups were the most appropriate? No mention on why certain participants were recruited, why not other. No mention of full response rate. 5. No published interview guide; unsure what the exact questions were. 6. Main researchers' relationship was considered with the professionals, but not the two others who analysed the data. 8. Not much mentioned on rigour, apart from mention on three analysts, also misinterpreted rigour with ethics.	6
Neher et al.	4. Dynamics within the group not considered. Dynamics between senior staff members and junior; 8. No mention on who transcribed the data.	8
Olsson Moller et al.	4. No mention how many people was contacted, no response rate; 8. no mention of who transcribed the data; no mention on how the researcher could have influenced the data analysis; no mention on the profession of the researchers, only that the first author know some of the participants	8
Payne et al.	3. no mention why individual interviews; what was the benefit? 4. 9 professionals mentioned, but only 6 took part. No mention on why other 3 did not participate. 5. No discussion on saturation, who transcribed the data? 6. No mention on relationship between researchers and participants. 10. lack of representativeness of ethnic minorities; not recruiting people with lower physical status	5
Romero-Elías et al.	5. No mention on the length of interviews 6. No reflection on how the interviewer and the analysis could have influenced the study. 9. No mention of potential limitations of the study design	7

Author	Issues identified on CASP	CASP score
Santa Mina et al.	4. Snowball sampling, it is possible they missed out on some populations; no reason why 6 coordinators declined participation; 5. no published interview guide; not transparent what were the questions; no saturation mentioned; not clear who transcribed the data; 6. Relationship between interviewer, analysts and participants not considered; 8. No reflexivity, triangulation or only content analysis used; 9. Finding seem a bit muddled at some parts. Clearer layout would have helped.	5
Shea et al.	4. No mention who was part of the allied health professional group; mentioned in the limitations that people who took part might have been keen and informed on physical activity and cancer; 5. no justification why telephone interviews were used; no published interview guide, no clear picture on interview questions; no mention on who transcribed the data; 6. No relationship examined between participants, interviewer and analysts	7
Smith-Turchyn et al.	4. No physiotherapists interviewed; volunteer bias; people might have signed up because they were interested in the findings; no response rate mentioned 6. No relationship between interviewer, researchers and participants; 8. No rigor mentioned: reflexivity, audit trail, triangulation? 9. Some claims and subthemes have no data to back it up;	6
Transforming Cancer Services Team	4. Recruitment strategy; not clearly explained why only commissioners involved; some areas did not respond to e-mails, only people involved who responded to e-mails? Selection bias? 6. Relationship between researchers and participants not mentioned; 7. ethical issues not considered; 8. no thematic analysis, more of a content analysis, with themes arranged under previously determined categories; However, must mentioned this is an engagement event not a full research project	6