

BMJ Open Exploring what influences the uptake of cancer rehabilitation services: a realist informed mixed-methods study

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ABSTRACT

Objectives To investigate how uptake of cancer rehabilitation services is affected by information provision and whether it is influenced by people's perception and attitudes towards rehabilitation interventions and therapies.

Design This study followed a realist informed mixed-methods design. Descriptive secondary analysis of a cancer rehabilitation database containing information about number of people attending services, their diagnosis and sex and semi-structured interviews with people affected by cancer (PABC) and healthcare professionals (HCPs) were conducted.

Setting Cancer rehabilitation services located in two cancer centres in South Wales, UK.

Participants PABC who received care from any of the included cancer rehabilitation services. HCPs providing cancer rehabilitation at any of the included services.

Interventions Exercise-based cancer rehabilitation, fatigue management, acupuncture and allied health professional support were provided as cancer rehabilitation.

Results Twenty HCPs and 15 PABC were recruited for semi-structured interviews across the two services. The number of database records used for the secondary analysis ranged from 212 to 347 between 2014 and 2017. Based on descriptive analysis of these records and thematic analysis of HCPs' interviews, uptake of cancer rehabilitation services often fluctuated. This could be attributed to PABC reporting issues with information provision on available services. Based on PABC's accounts, they learnt about cancer rehabilitation in various ways, often by chance via word of mouth. Information provision was influenced by several issues including lack of consensus on what cancer rehabilitation means, the wider multidisciplinary team's (MDT) perception and knowledge on cancer rehabilitation, the prevailing medical model in healthcare and the lack of routine provision of services. The perception and attitude of PABC did not seem to inhibit uptake and information provision.

Conclusions To modify these inhibiting issues, the education of the wider MDT regarding the aim, modalities and importance of cancer rehabilitation is crucial.

INTRODUCTION

With continuing developments in cancer screening and treatments, more people are living with and beyond cancer. However, a

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Realist methodological framework guided this study, providing a rich, detailed middle-range theory that helped identify service uptake issues with two cancer rehabilitation services in South Wales.
- ⇒ This middle-range theory can help identify the elements of healthcare provision that need to be addressed to optimise cancer rehabilitation uptake.
- ⇒ A limitation is that interviewing the wider multidisciplinary team and people affected by cancer (who did not receive cancer rehabilitation from any of the investigated services) was out of the scope of this study, thus it is possible that further contextual influences and issues surrounding cancer rehabilitation provision could exist.
- ⇒ A limitation of the descriptive secondary data analysis is that out of the two cancer rehabilitation services investigated, only one of them collected service data, hence the full extent of service uptake issues cannot be determined.
- ⇒ This study is part of a wider body of work, so not all middle-range theories tested and developed could be presented in this paper.

cancer diagnosis and its treatments can have life-altering consequences. Long-term effects, including fatigue, mobility problems, pain, breathlessness, malnutrition and depression, are health issues that develop during treatment and can have lasting impact up to 5 years or longer.^{1 2} Late treatment effects can be defined as physical or psychological health problems, including cardiovascular toxicities, reduced bone density or hypothyroidism that present 6 months or later post-treatments and could affect whole organ systems.¹⁻³ While evidence is lacking on the prevalence of long-term and late treatment effects in the adult cancer population, estimates are available for some.¹ For example, an estimated one-quarter to one-third of people affected by cancer (PABC) experience fatigue post-treatment.¹ In the UK, long-term and late treatment effects were estimated to affect 25% of PABC.⁴ Moreover, cancer-related disability that influences the performance of



basic activities of daily living could affect approximately 36.7% of PABC worldwide.⁵

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.^{6,7} Several definitions of cancer rehabilitation exist internationally, but most consider cancer rehabilitation a service which helps people achieve maximal functioning, independence and adaptation to changes caused by cancer and its treatments.^{8–10} The concept of cancer rehabilitation should also encompass a holistic view of PABC¹⁰ and consider the impact cancer has on people's families and social environments.¹¹ Additionally, cancer rehabilitation is increasingly considered as an intervention that should be provided throughout the cancer continuum from diagnosis (prehabilitation) to the end-of-life.¹⁰ Physical exercise, dietary advice, speech and language therapy, psychological support and health education are some of the many interventions that can be provided as cancer rehabilitation alone, or in combination depending on the individuals' needs.

Cancer rehabilitation is increasingly being included in clinical guidelines, with a systematic review identifying 69 documents either recommending referral to cancer rehabilitation services or providing information on rehabilitation assessment and interventions.¹² However, regardless of recommendations, provision of and access to cancer rehabilitation is not widespread. Evidence from the past 10 years, predominantly from the USA, suggests that only 2%–9% of PABC are referred to cancer rehabilitation.^{12,13} In Wales (UK), responses to the Wales Cancer Patient Experience Survey (WCPES) in 2016 indicated that 41.3% of participants who needed practical advice and support (including exercise and diet) received limited (26.8%) or no care (14.5%).¹⁴ The same survey, repeated in 2021, showed a further decline in support received, with 54% of respondents indicating limited (34%) or no support (20%). However, the survey was distributed during the COVID-19 pandemic, which may have influenced the responses.¹⁵ However, reasons for the insufficient support in Wales prior to the COVID-19 pandemic are unclear. Thus, the broad aim of this mixed-methods study was to investigate what works for two cancer rehabilitation services in South Wales, for whom, in what circumstances and how.

Self-determination theory is a behaviour change concept that could be applied to cancer rehabilitation to better understand how it works and what mechanisms lead to issues with accessing services. Self-determination theory holds that to develop and maintain a new behaviour, the values and skills needed for change need to be internalised by individuals.¹⁶ This process of internalisation can be maximised by fulfilling three psychological needs: autonomy, competence and relatedness.¹⁶ Autonomy relates to volition, meaning that the required behaviour is in line with the individual's integrated values, beliefs and sense of self.¹⁷ Competence refers to the skills and confidence needed for change, while relatedness concerns the

human connections needed to support adoption of new behaviours.^{16,18}

Previous research applying self-determination theory has suggested that interventions tailored to satisfy the three psychological needs could be beneficial in engaging people in exercise-based or other rehabilitation activities. Such tailoring could include teaching skills, non-controlling coaching style, positive feedback and information on the benefits of rehabilitation to support the autonomy and competence of PABC.^{19–21} While information on rehabilitation might support autonomy and competence, international qualitative research investigating cancer rehabilitation, more specifically exercise, has found that insufficient information provision was reported by PABC as one of the barriers to accessing services.^{22,23} Furthermore, PABC often mentioned that they did not know where to go to get help or what exercises to do.^{22,23}

However, information about cancer rehabilitation in itself may not be enough to help engagement with services. PABC on the receiving end of rehabilitation interventions would also need to be motivated to attend services. Evidence from the available literature showed that people who did not enjoy exercising prior to their cancer diagnosis were less likely to engage in exercise-based cancer rehabilitation compared with those who had an active lifestyle.^{22–26} From a self-determination theory perspective, this lack of enjoyment implies that some PABC may not have intrinsic or autonomous motivation to exercise. Hence, a more specific aim of this mixed-methods research study is to investigate how uptake of cancer rehabilitation services is affected by information provision and whether it is influenced by people's perception and attitudes towards rehabilitation interventions and therapies.

METHODS

To explore how cancer rehabilitation works in South Wales and how information provision and people's perception could influence service uptake, a mixed-methods realist informed evaluation was identified as an appropriate methodology. Realist evaluation is a methodological framework, allowing the investigation of how a service works for whom and in what circumstances.²⁷ With the inclusion of circumstances, realist evaluation explores the wider context in which a service is implemented, as clinical, social, cultural and political settings can have a real impact on a service.²⁸ For these attributes, realist evaluation is a good fit for the exploration of complex interventions, such as cancer rehabilitation that can have multiple components. The reporting of this study follows the Realist And Meta-narrative Evidence Syntheses: Evolving Standards (RAMESES) II standards for realist evaluations.²⁹

Realist evaluation is a theory-driven methodology, meaning that based on the underlying theoretical framework of the service under investigation, middle-range theories are developed at the commencement of

research.²⁷ Middle-range theories, or initial programme theories (IPTs) as referred to in realist research, can be defined as empirical hypotheses that are transformed into broad statements that can be tested, verified, refuted and refined by data.³⁰ The unit of analysis in realist evaluation is context-mechanism-outcome (CMO) configurations.²⁷ Mechanisms (M) define how a service brings change and what response it triggers in the target population.²⁷ Context (C) refers to any circumstance that can support or inhibit a mechanism, including the clinical and cultural environment.²⁷ Mechanisms can work differently in various contexts resulting in both expected and unexpected outcomes (O).

Initial programme theory

For this study, IPTs were developed by reviewing the research and policy literature on cancer rehabilitation and through discussions with a dedicated project Steering group, the members of which were ‘programme architects’. Programme architects can be described as the developers or leaders of a service under investigation.²⁷ Using steering groups for IPT development is considered an efficient way to involve busy professionals.³¹ Following these processes, four IPTs were developed, out of which this paper is focusing on the testing of one: *raising awareness on available cancer rehabilitation services in South Wales, and appropriate information on their purpose (mechanism) can increase their uptake (outcome) if people’s perception and attitudes are supportive of cancer rehabilitation (context)*.

The rest of this research study focuses on how this IPT was tested and refined by investigating whether the mechanism of information provision worked differently or whether any other contexts existed that could influence it and how these led to service uptake changes. Further detail of the whole project can be found in the published protocol.³² No significant deviations were made from the protocol for this study.

Setting

To test the IPT, cancer rehabilitation services (n=2) located in two cancer centres in South Wales were investigated. The exploration of two service models had the potential to represent the wide-ranging nature of cancer rehabilitation. To protect the identity of the services, they will be referred to by pseudonyms. The Willow Team provided inpatient and outpatient services led by specialist occupational therapists (OTs) and physiotherapists with connection to other allied health professionals (AHPs). Services were tailored to the needs of PABC based on a modified version of the concerns checklist.³³ Inpatient care was focused on the support of acutely unwell PABC. As part of the outpatient service, one-to-one sessions or 12-week group classes in Tai-Chi, hydrotherapy and circuit training were offered, with both gentle and advanced options. This approach provided more variety, allowed for tailoring to individual needs and gave participants the opportunity to progress to more challenging activities. People with any

type of cancer at any point in the cancer continuum were eligible to attend the services.

The Fern Team provided specialist inpatient and outpatient dietetics, speech and language therapy, OT and physiotherapy services. They mainly saw PABC during active treatments, who were usually referred back to their local hospital or community teams for more support following the end of their treatments. Similar to the Willow Team, inpatient care aimed to support individuals with acute and complex issues. However, outpatient care was more varied, including acupuncture and Pilates classes for people with breast cancer by physiotherapists, dietetic drop-in clinics and OT-led fatigue management groups for individuals with any cancer diagnosis. Rehabilitation planning was based on initial assessment by AHPs and considered the person’s individual goals and requirements, although no formal needs assessment was provided.

Data collection methods

Mixed-methods research is often recommended in realist evaluation to test different elements of the IPT.³⁴ Qualitative interviews can help investigate mechanisms, while for testing contexts both quantitative and qualitative methods can be used, depending on whether new or different contexts are expected to be found.³⁴ To determine outcomes, quantitative methods are often used, although qualitative methods can uncover new or unexpected outcomes.³⁵

In this study, one-to-one semi-structured interviews were conducted with both healthcare professionals (HCPs) and PABC to investigate underlying mechanisms, influencing contexts and unexpected outcomes, as including both the perspectives of healthcare providers and users is considered the best way to learn how and why a service works.³⁶ Moreover, secondary analysis of routinely collected service data were used to explore cancer rehabilitation service uptake as the main outcome. Ethical approval for the study was granted by London - South East Research Ethics Committee (17/LO/2123).

Secondary analysis of routinely collected data

A database collected by the Willow Team between 2014 and 2017 was analysed to investigate service uptake of the outpatient one-to-one and group exercise classes. The database contained information on attendees’ sex, diagnosis, exercise class type, prerehabilitation and post-rehabilitation outcome measure results and the number of rehabilitation episodes provided. The Willow Team referred to a 12-week long class as a ‘rehabilitation episode’. It was possible for people to attend several rehabilitation episodes depending on their needs, and for some PABC up to 12 episodes were recorded. For the purposes of investigating uptake of PABC, episodes 0 and 1 were used, as these were indicative of how many people newly accessed the services. Episode 0 was used from 2014 to 2016 to mostly refer to PABC who contacted the Willow Team, received an appointment, but never showed or

disengaged after the initial assessment. From 2016 onwards, most PABC who did not show were included in episode 1. Episode 0 was included in the descriptive analysis, as these implied that participants were either referred or aware of the service, even if they did not engage in the long term.

For this IPT, yearly episode 0 and 1 numbers, attendees' sex and diagnosis data were analysed. The Willow Team database did not include inpatient data, so the secondary analysis is focused on their outpatient services. Moreover, the Fern Team did not collect an electronic database during the same time period, thus, no comparison was available.

Descriptive data analysis

For this secondary analysis, it was theorised within the IPT that uptake (number of episodes 0 and 1) would increase over time as the rehabilitation service became more established and more information about it was provided. It was also expected that the number of episodes would follow the forecasted increasing cancer prevalence trend.³⁷ Furthermore, it was expected that attendees' cancer diagnosis would follow the same trend as the most common local cancer incidence and prevalence rates, meaning that people with breast, lung, colorectal and prostate cancer would have the most rehabilitation episodes. To analyse these trends, a descriptive graphical presentation was conducted, as graphs and charts can enable the visualisation of big samples in a compact, yet coherent way.³⁸ In addition, graphical methods can reveal multiple levels of detail and fine structures providing an overview of the data.³⁸

Where graphs and charts indicated unexpected tendencies in uptake of PABC, consultations were arranged with the Willow Team. The aim of these consultations was to explore any change in staff or service provision that could possibly explain discrepancies in the data.

Semi-structured interviews

A purposive sample of cancer specialist HCPs (dietitians, physiotherapists, speech and language therapists (SLTs), OTs and assistants) and PABC was recruited from the Willow and Fern Teams between March 2018 and May 2019. Recruitment of HCPs was supported by Steering group members, who promoted the study and shared invitation letters and participant information sheet with the staff of the Willow and Fern Teams. Interested HCPs could contact the lead author directly via the details on the invitation letters, thereby ensuring confidentiality. The recruitment of PABC was supported by HCPs working at the Willow and Fern Teams. HCPs distributed invitation letters and response slips to eligible PABC at their first appointment or re-assessment for a new rehabilitation episode. Potential participants were asked to read the invitation letter and contact the lead author directly via post, telephone or email if they were interested in participating. This way PABC could keep their response confidential. People affected by cancer, who

wished to have a companion with them, were supported to bring a family member, friend or a carer along. Detail about inclusion and exclusion criteria can be found in the published protocol of this work.³²

Semi-structured interviews were conducted, as these provide both structure and flexibility to investigate the IPTs.³⁹ Realist interview is the widely accepted method for realist evaluation, although it has its critique.^{31 40} Research accounts exist describing potential for confirmation bias or acquiescence while conducting realist interviews,^{31 40} thus the decision was made to use a broad topic guide with only microelements of the IPT for this study. Hence, this mixed-methods research is referred to as a realist informed evaluation. Interview topic guides for HCPs and PABC with open-ended questions (online supplemental material 1) were developed based on the cancer rehabilitation literature, the IPT and consultation with the Steering group. Specifically, to test the mechanism of information provision, questions regarding how participants learnt about cancer rehabilitation and how they got in touch with services were asked, while HCPs were inquired about common referral routes. To test the proposed context of participants' perceptions and attitudes, questions were asked around what cancer rehabilitation meant for them, whether they were aware who provided care for them, what were their expectations prior to attending services and whether there were any issues that made it difficult for them to attend cancer rehabilitation services. HCPs were inquired about the difficulties they faced around service provision.

Participants were free to choose the time and location of the interview, which were mainly conducted at their own home, or at university facilities. All interviews were led by the lead author who was a novice qualitative researcher working on a doctoral thesis at the time. The lead author was a qualified and registered physiotherapist, who had not worked in cancer rehabilitation and had no prior link to either the HCPs interviewed or PABC. Interviews were digitally recorded, and transcribed verbatim by the lead author.

Qualitative data analysis and combining qualitative and quantitative data

Reflexive thematic analysis of interview data was broadly followed as an analytic approach to identify not just simply themes, but also contexts, mechanisms and outcomes.⁴¹ Reflexive thematic analysis does not belong to any theoretical framework and it is usually considered realist, thus, it can be used with different methodologies. Retroduction, commonly used in realist evaluations, was also applied to find causal relationships across the data.⁴² Retroduction uses both inductive and deductive reasoning along with the researcher's insights, expertise and abstract thinking.

Interview transcripts were coded by the lead author, while the second and third authors checked data extracts to determine whether the lead authors' interpretation was accurate to ensure dependability and rigour. To ensure trustworthiness of the analysis, a clear audit trail

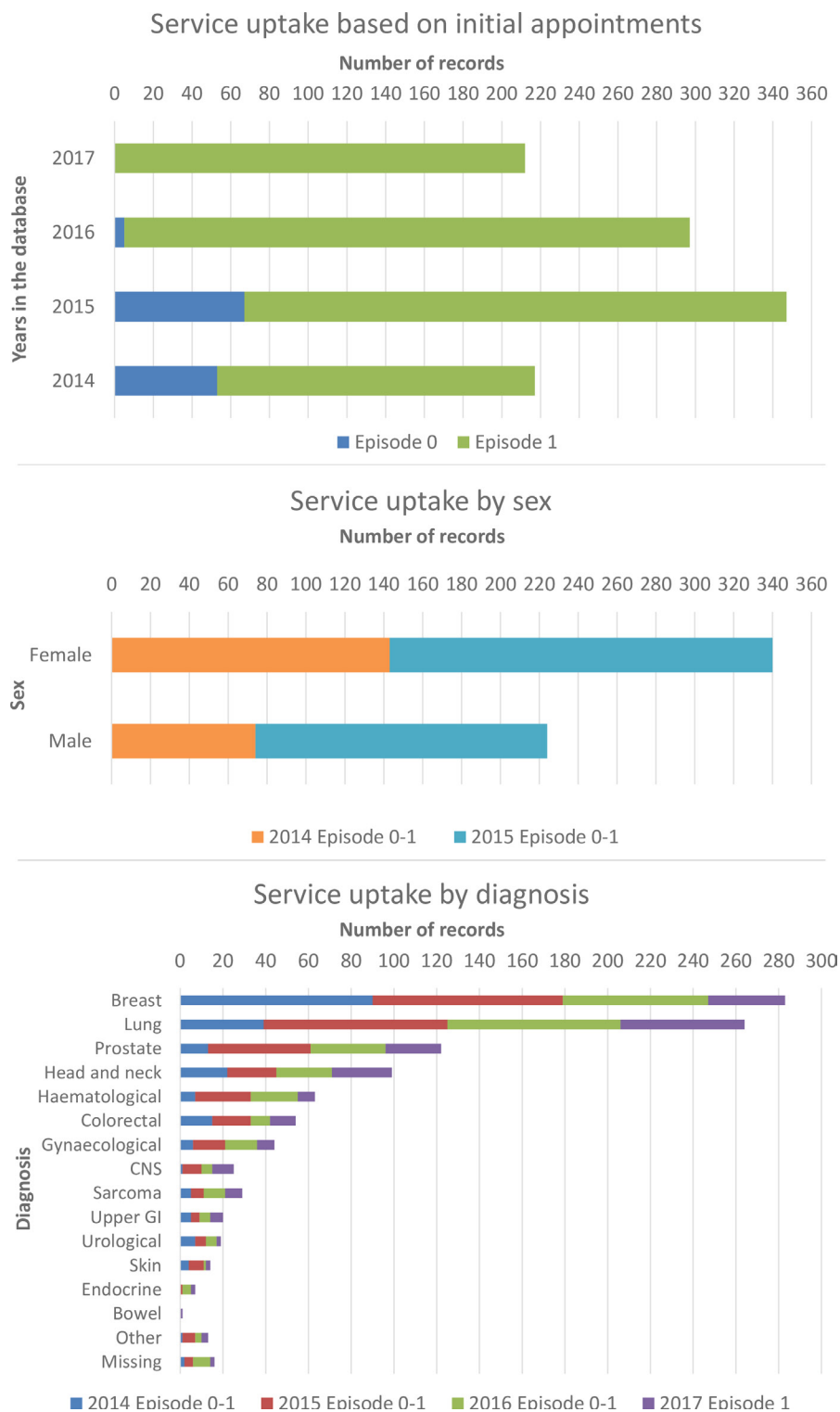


Figure 1 Descriptive analysis of the uptake of the Willow Team across the years, diagnoses and sex of people affected by cancer. CNS, central nervous system; GI, gastrointestinal.

was maintained, and thick descriptions, along with a reflective diary, were also documented.

The codes from this qualitative analysis and the findings of the quantitative descriptive analysis were integrated into a new CMO configuration using joint displays and triangulation.^{43–45} When interpreting the findings, qualitative codes and quantitative data were mapped

onto the original IPT in Microsoft Excel to determine similarities and differences between the IPT and the new emerging findings. Joint displays, such as the use of tables within Microsoft Excel, aid visualisation and integration of findings from different data sources.⁴⁴ Moreover, the findings were triangulated, meaning that it was explored whether data from different sources, such as routine data

Table 1 Characteristics of interviewed healthcare professionals

	Participants	Profession	Experience in cancer rehabilitation
Willow Team	Professional_01	OT	16 years
	Professional_10	Technician	7 years
	Professional_11	SLT	5 months in current role+5 years in another hospital
	Professional_14	OT	10 years
	Professional_15	Physiotherapist	5 years
	Professional_16	OT	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	OT	16 years on and off
Fern Team	Professional_02	SLT	2 years
	Professional_03	Technician	1 year and 3–4 months
	Professional_04	Dietitian	3 years and 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	SLT	5 years
	Professional_12	OT	4 years
	Professional_13	SLT	1 year and 2 months in current role+18 years in other hospitals

OT, occupational therapist; SLT, speech and language therapist.

and qualitative interviews, were in agreement or complemented each other.⁴⁵ In this study, findings from the two different data sources complemented each other, leading to expansion of what is known about cancer rehabilitation uptake.^{44 45} Following this process, new contexts and mechanisms were identified and different causal relationships between data extracts were discovered. Therefore, the original IPT was redesigned into a final CMO configuration. The new findings from the data were discussed between the authors. The identified new contexts and mechanisms are presented in the ‘Findings’ section.

Patient and public involvement

A patient involvement facilitator and a local cancer charity representative were active members of the project Steering group and helped in the design and development of this study.

FINDINGS

Outcome: uptake of cancer rehabilitation services

The findings of the descriptive analysis showed that uptake of the Willow Team fluctuated over the years. The number of database records, as depicted in [figure 1](#), increased from 217 in 2014 to 347 in 2015. However, this increase was followed by a drop to 297 in 2016. A further

drop was observed in 2017, with the Willow Team only seeing 212 PABC, more than a quarter less than in 2016. This is not in line with the increased uptake theorised in the IPT.

Additionally, it was theorised that people diagnosed with breast, lung, colorectal or prostate cancer would have the most episodes in the database. However, as seen in [figure 1](#), while breast, lung and prostate cancer was among the four most common diagnoses that people attended the Willow Team with, the fourth most common diagnosis at the rehabilitation service was head and neck cancer. Moreover, variations in service uptake of different cancer sites were also observed over time. The number of people with breast cancer reached a peak in 2015 (n=97) and dropped in 2017 (n=36), halving the previous years’ uptake. Lung cancer cases peaked in 2016 (n=81) and dropped in 2017 (n=58), and a decrease in 2017 was also noticeable for prostate, gynaecological and haematological cancers. However, uptake among people with central nervous system, head and neck, colorectal and upper gastrointestinal cancers increased in 2017 compared with 2016.

Although data on the sex of PABC were only available for 2014 and 2015 due to changes in administration, when investigating uptake by sex, a major difference

can be noticed between male and female participants. **Figure 1** shows that in 2014 and 2015 more female participants (n=340) contacted the Willow Team than male participants (n=224). In 2014, almost twice as many female participants (n=143) were referred to the rehabilitation services than male participants (n=74). However, in 2015 the number of male participants contacting the Willow Team doubled (n=150). The increased uptake among male participants could be partially attributed to the rise in the number of people with prostate cancer. The number of individuals with prostate cancer nearly quadrupled from 2014 (n=13) to 2015 (n=48).

While the Fern Team did not have a database for the same period, data from the semi-structured interviews suggested that fluctuation in the number of participants or poor uptake might have existed.

[...] 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 that. (Professional_04—dietitian)

To fully understand causal relationships behind the fluctuation in the uptake of people, different diagnoses and sex, an exploration of the mechanisms and contexts was necessary.

Mechanism: inconsistent or insufficient information provision

Initially, it was theorised in the IPT that providing information on and raising awareness of available cancer rehabilitation services was the mechanism leading to increased uptake. However, as seen above, uptake of the services

fluctuated. This was partially the result of issues identified with information provision, as uncovered by qualitative interviews. For the qualitative interviews, 20 HCPs and 15 PABC were recruited across the two services. Participant characteristics are detailed in **tables 1 and 2**. Interview recordings ranged from 26 to 96 min. Three participants (participants 10, 16 and 28) had their partners with them, thus resulting in dyadic interviews.

The qualitative findings suggest that while information provision itself seemed to work to increase knowledge about rehabilitation, there was a lack of consistency in the ways information was given, such as in the personnel providing it. Seven participants recruited from the Willow and Fern Teams learnt about rehabilitation services from oncology nurses, their oncologists or from AHPs working in settings other than oncology. While two participants reported straightforward access to rehabilitation services this way, others mentioned not knowing who they can talk to about their health issues or only receiving information if they explicitly raised concerns about long-term effects.

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... they could delve in a bit more to what was going on with you. (Participant_21—person affected by breast cancer)

One participant reported raising their cancer treatment-related side effects to members of the multidisciplinary team (MDT) only for their issues to be dismissed initially as being age related.

When I mentioned fatigue, when I was seeing the urologist they kind of said 'Fatigue? That's your age'. And they

Table 2 Characteristics of interviewed people affected by cancer

	Participants	Diagnosis	Sex	Age group (years)	Intervention	Work status
Willow Team	Participant_01	Prostate	Male	65–69	Circuits	Retired
	Participant_02	Colorectal	Female	60–64	Tai Chi	Retired
	Participant_03	Breast	Female	70–74	Tai Chi/Circuits	Retired
	Participant_09	Prostate	Male	60–64	Hydrotherapy/Circuits	Retired
	Participant_10*	Prostate	Male	70–74	Hydrotherapy	Retired
	Participant_12	Prostate	Male	80–84	Hydrotherapy	Retired
	Participant_16*	Prostate	Male	65–69	Circuits	Retired
	Participant_28*	Breast	Female	70–74	Hydrotherapy/Circuits	Retired
	Participant_30	Prostate	Male	75–79	Circuits	Retired
Fern Team	Participant_18	Breast	Female	65–69	Acupuncture	Retired
	Participant_21	Breast	Female	35–39	Acupuncture	Teacher
	Participant_27	Lung	Male	55–59	Dietitian/SLT	Retired
	Participant_29	Prostate	Male	65–69	Fatigue management	Retired
	Participant_37	Breast	Female	40–44	Fatigue management	Civil engineer
	Participant_39	Thyroid	Female	60–64	SLT	Self-employed

*Dyadic interview.

didn't kind of... connect with that at all. 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)

Three participants learnt about the Willow Team through accessing a local charity-run support centre (Pine Centre), and some of them and their companions expressed frustration, as they would not have learnt about the rehabilitation service any other way.

If we didn't go to Pine Centre, we wouldn't have learnt about the Willow nurses, and 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 thing to have it... more advertised. (Companion_16—wife of participant_16)

Other participants mentioned education courses and information leaflets as the ways they learnt about the cancer rehabilitation services.

Well, I mean I knew Willow was there, but... 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... 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)

One participant described the issues with information provision and referrals as services being disjointed and information spreading via word of mouth, indicating that there was a lack of information provided by the MDT at treating 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. 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 breast cancer)

Context: people's perceptions, the wider MDT's knowledge, medical model and the lack of routinely provided cancer rehabilitation services

The IPT theorised that people's perception could be the context that influences service uptake. If people had initial prejudices towards rehabilitation, they would not want to attend the services despite being provided with relevant information on what rehabilitation services to access. However, based on the interviews with PABC, the issue was not their perception of rehabilitation being

something physical or exercise-based, as even PABC who were not into exercising and fitness before their diagnosis were willing to attend.

I was petrified of the gym. I had never been in... a gym in my life and... I said to the Willow girls 'Oh, no, I can't stand it. 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)

In addition, some HCPs mentioned that PABC did not refer to their services as rehabilitation, indicating that people might be less interested in what is provided or how it is labelled and more interested in improving their quality of life.

[...] 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)

Another aspect of rehabilitation perceptions was that many participants were unaware of their HCPs' roles: physiotherapists and OTs were often referred to as nurses. However, PABC's insufficient knowledge of professional roles did not seem to majorly hold them back from attending the rehabilitation services.

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)

What seemed to inhibit the mechanism of information provision was the perception of the wider MDT. This is supported by the lack of consistency in how PABC learnt about the cancer rehabilitation services, and it seemed that PABC often learnt about cancer rehabilitation from sources outside of their cancer treatment centre where Willow and Fern were also located. HCPs reported that physicians, 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, we're not an add-on, we can actually enhance the services and enhance the quality of care. But that's not always seen until the end. (Professional_06—physiotherapist)

Based on HCPs' experiences, some of these perceptual issues might have stemmed from the ever present medical model in healthcare and the lack of holistic care, perpetuating that cancer treatments had higher priority than long-term and late treatment effects and PABC's quality of life.

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)

Additionally, the wider MDT's knowledge limitations regarding cancer rehabilitation impacted their ability to make referrals to services. Many interviewed HCPs reported that the wider MDT did not always know that cancer rehabilitation services existed within their respective cancer centre.

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. (Professional_14—OT)

In addition to HCP interviews, based on the consultations with the Willow Team, the observed drop in breast cancer cases in 2017 depicted in [figure 1](#) was due to the wider MDT's lack of knowledge. The Willow Team had a physiotherapist, who acted as a contact to other services, such as the lymphoedema team. However, while this physiotherapist was on extended leave from March 2017, these services stopped referring to the Willow Team. The reason for the drop in referrals was that these services thought that the Willow Team could not provide the same rehabilitation interventions as the physiotherapist. Due to these issues with the wider MDTs' knowledge and perception of cancer rehabilitation, service promotion is important. Professional_19 highlighted that providing an education session for a haematology department in their local cancer centre helped increase the knowledge of the haematology staff and the number of referrals.

[...] Therapist_03 did a... in-service training with them [Haematology department] 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)

These perceptual and cultural issues of the wider MDT might be exacerbated by the lack of consensus among HCPs on what cancer rehabilitation means. The 20 HCPs interviewed gave various responses regarding what rehabilitation meant to them. Many articulated that rehabilitation was all-encompassing, providing input from diagnosis until the end-of-life.

I see cancer rehabilitation as encompassing at any... being utilised at any part of 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)

Other HCPs expressed that rehabilitation was very much dependent on the cancer site and PABC's needs, with traditional rehabilitation considered as recovery or restoration.

In my head the term changes depending on 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)

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 colleagues understand this, because cancer rehabilitation is so broad. (Professional_14—OT)

Finally, a context that largely influenced 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)

Additional data extracts illustrating the identified mechanisms and contexts are presented in [table 3](#).

DISCUSSION

Summary of findings

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, testing this theory through the findings showed that uptake of both the Willow and Fern Teams fluctuated and it could be attributed to PABC reporting issues with the provision of information on available cancer rehabilitation services. The perception and attitude of PABC did not seem to inhibit uptake and information provision as originally theorised in the IPT.

Contexts that were identified as impeding the mechanism of information provision was the wider MDT's perception, insufficient knowledge and the medical culture. These perceptual and cultural issues were exacerbated by the lack of consensus among HCPs on what cancer rehabilitation means. Moreover, cancer rehabilitation is not routinely integrated into the cancer pathway, meaning that PABC will not necessarily see a rehabilitation professional unless they are referred 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 2](#), which shows the refined CMO.

Table 3 Additional data extracts illustrating the mechanisms and contexts

Part of the CMO	Code	Data extract
Mechanism— inconsistent or insufficient information provision	Learning about rehabilitation from local charity-run support 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) “[...]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)
	Education courses and information leaflets	“Well, cos it’s 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”. (Participant_18—person affected by cancer)
Context—people’s perceptions	Patients not using the label ‘rehabilitation’	“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)
	PABC’s insufficient knowledge of professional roles	“Then I was recommended to go to the gym in Yew Hospital with the Willow nurses”. (Participant_16—person affected by prostate cancer)
Context—the wider MDT’s perception and knowledge, and the medical model	Cancer rehabilitation seen as an add-on	“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 service. So I would like to see the recognition”. (Professional_09—SLT)
	Ever present medical model	“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) “[...]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) “I think the culture within the NHS, because it’s very focused on nurses and doctors that has to change”. (Professional_18—dietitian)
	Wider MDT’s lack of knowledge	“[...]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 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 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)

Continued

Table 3 Continued

Part of the CMO	Code	Data extract
Context—lack of consensus on what cancer rehabilitation means	Cancer rehabilitation does not equal traditional rehabilitation or restoration Rehabilitation is a fuzzy word	“So, I’m in a bit of a quandary by the 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) “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)
Context—rehabilitation is not routinely provided in the cancer pathway	Cancer rehabilitation is not routinely provided	“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)
CMO, context-mechanism-outcome; MDT, multidisciplinary team; NHS, National Health Service; OT, occupational therapist; PABC, people affected by cancer; SLT, speech and language therapist.		

Comparison with existing literature

As seen above, the descriptive analysis of a cancer rehabilitation database showed a fluctuation in the uptake of PABC. While the findings of this realist-informed evaluation suggest that information provision issues and the wider context are related to this uptake fluctuation, other factors not reported as part of this IPT could also contribute. As seen in the wider literature, staff capacity could lead to care provision issues, leading to reduced uptake.^{46 47} Staff capacity has been investigated as part of the wider project (Realist evaluation and economic analysis of cancer rehabilitation services in South Wales (REECaRS)),³² although it was more related to another IPT, the findings of which are reported elsewhere.⁴⁸ Additionally, staff capacity issues do not explain the poor attendance of PABC reported by HCPs working for the Fern Team.

Another factor influencing patient uptake not directly investigated in this study could be the incidence and prevalence of cancer. In this study, breast cancer and lung cancer were the two most dominant diagnoses among cancer rehabilitation attendees at the Willow Team. This reflects the rate of new local cancer cases, as breast cancer (n=1391) and lung cancer (n=1302) were the two most prevalent diagnoses from 2014 to 2017.⁴⁹ Colorectal cancer (n=1137) had the third highest number of new cases between 2014 and 2017 in the local area.⁴⁹ However, this was not reflected in the uptake numbers of the Willow Team, as colorectal cancer was the sixth most common diagnosis among participants (n=54) during the same period. Despite this, emerging evidence suggests that a high proportion of patients with colorectal cancer have physical and psychological rehabilitation needs.⁵⁰ Prostate cancer (n=1086) had the fourth highest number of new cancer diagnoses in the local area between 2014 and 2017. People affected by prostate cancer can face severe long-term and late effects,⁵¹ although only 122 were referred to rehabilitation during this period. Moreover, incidence of prostate cancer was consistent between 2014 and 2015, with 228 new diagnoses reported in the local area each year.⁴⁹ Therefore, the sudden increase in prostate cancer uptake of the Willow Team cannot be explained by a rise in incidence.

What further supports the findings of the descriptive analysis is the WCPES results. People affected by breast cancer were most likely to receive practical support with their long-term and late effects (63.4%, n=1449) in all of Wales in 2016.¹⁴ Moreover, when breaking down the WCPES responses by region, practical support provision in the local area of the Willow Team (65%, n=257) was higher than the national average for Wales.¹⁴ This supports the findings of the descriptive analysis that people affected by breast cancer were more likely to access cancer rehabilitation interventions of the Willow Team and receive support. Moreover, the findings of the descriptive analysis align with the international trend, in that breast cancer historically had the highest representation in the cancer rehabilitation and supportive care

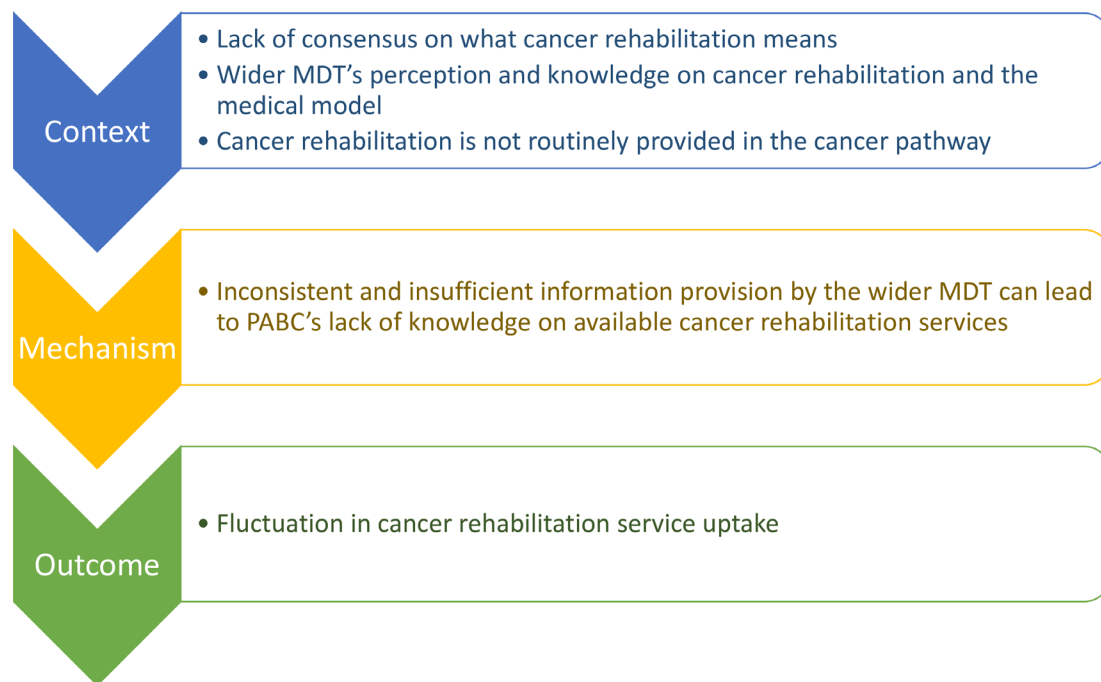


Figure 2 Refined context-mechanism-outcome configuration. MDT, multidisciplinary team; PABC, people affected by cancer.

literature.^{52 53} On the other hand, 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 long-term and late effects (20.3%, n=128) compared with the all-Wales responses (16.4%, n=807).¹⁴ These WCPES results could reflect the uptake issues of the Willow Team regarding people affected by prostate cancer. However, while the WCPES results support the findings of this realist-informed evaluation, it must be considered that survey results cover a sizeable geographical area, with numerous hospitals within one location. It could be possible that PABC located in the area of the Willow Team received generic support from another hospital or a charity-run support service, which met their cancer rehabilitation needs. However, it was out of the scope of this study to investigate all support services that could help PABC.

Moreover, in the descriptive analysis differences were identified in the uptake of PABC based on their sex, with more female participants attending the exercise classes of the Willow Team. Evidence from the wider literature suggests that men were often not offered rehabilitation opportunities due to the MDT's perception of masculinity and gender.⁵⁴ While this realist-informed evaluation did not specifically investigate the reasons behind differences in uptake based on participants' sex, it might be possible that the MDT's perception of gender roles influenced information provision about cancer rehabilitation.

In this study, the potential mechanism behind the uptake issues was the inconsistent or insufficient information provision. Evidence from the wider literature supports this mechanism, as multiple accounts exist both from the UK and internationally regarding insufficient information provision on exercise and rehabilitation

opportunities throughout cancer treatments.^{22 23} The results of this study also align with self-determination theory, which suggests that if PABC do not receive information about the value and benefits of cancer rehabilitation, they will lack the competence to engage with these services.²⁰ Interviews with PABC in this study indicate that even though they received information in various formats, it enabled them to make decisions about their care and attend cancer rehabilitation, thus potentially satisfying their need for competence.

However, competence in itself is not enough to result in behaviour change and as a result, increase rehabilitation uptake. Autonomous motivation is also necessary based on the self-determination theory.¹⁶ Regarding autonomous motivation, the majority of the participants, particularly the subgroup attending the exercise classes provided by the Willow 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 before attending their first session. Thus, their autonomy did not need to be supported to engage with the Willow Team. However, active lifestyle does not explain the motivation of participants who attended the Fern Team's services, which were not exercise-based and included acupuncture and fatigue management. Hence, it is possible that their autonomy was also supported alongside their competence to engage with the Fern Team when they received information about the cancer rehabilitation services.

However, without the right information, neither participants' autonomy nor their competence can be supported to engage with cancer rehabilitation services. This is a particular issue, as due to the lack of integrated care and routine service provision, PABC can be discharged from

cancer services without ever being offered rehabilitation. Lack of integrated cancer rehabilitation in the treatment pathway has been reported internationally.^{55–58} However, it must be mentioned that since the publication of the National Health Service Long Term Plan, rehabilitation, particularly prehabilitation, has received greater attention, aiding its integration into treatment pathways in the UK.⁵⁹ In Wales, the recently published Cancer Improvement Plan also outlined steps to integrate prehabilitation into the cancer pathway.⁶⁰ However, the Cancer Improvement Plan is particularly focused on prehabilitation, thus HCPs need to ensure that rehabilitation throughout and following treatments are also equally embedded into cancer pathways. Hence, addressing the ever-present medical model and educating the wider MDT is crucial.

Many HCPs in this study reported the persisting medical model as a potential inhibiting context. This finding aligns with the wider literature, which shows that the medical model often manifested in the prioritisation of pharmaceutical and surgical treatments compared with cancer rehabilitation.⁵⁵ Moreover, the conservative thinking of certain medical professionals and ‘traditional values’ have been found to be a barrier to the implementation of exercise classes specific to PABC,⁶¹ even though current national and international guidelines recommend rehabilitation interventions.^{9 12 62} Prominent figures in oncology physiotherapy in the UK also argued that the medical model was a barrier to the provision and the development of cancer rehabilitation services.⁶³ Therefore, education of the wider MDT is necessary. There is emerging evidence that staff education might improve cancer rehabilitation referrals.⁶⁴

Strength and limitations

Realist methodological framework guided this study, providing a rich, detailed CMO configuration that helped identify service uptake issues with two cancer rehabilitation services in South Wales. This is the first study in Wales that investigates the supporting and inhibiting contexts faced by cancer rehabilitation services and presents causal relationships in a model. This model could help understand what elements of healthcare provision needs to be addressed to meet PABC’s needs and improve their quality of life.

While the findings can be useful for service improvement, the study also has some limitations. The sample size for the qualitative interviews was relatively small, particularly from the Fern Team, which could pose an issue as PABC in their care received different interventions, including fatigue management, acupuncture, SLT and dietitian input. This could limit the transferability of the findings. Additionally, interviewing PABC, who did not receive interventions from either of the two rehabilitation services, as well as members of the wider MDT, was beyond the scope of this study. Therefore, it is possible that other contexts and mechanisms exist that could influence service uptake.

Regarding the quantitative analysis, the Willow Team did not collect data on their inpatient ward activity, so it is not possible to present the true extent of their service uptake. However, data collection in rehabilitation services is a historical issue, and research in recent years have identified these problems.⁴⁶ Solutions have been offered and guidance are available for the minimum set of data that all cancer rehabilitation services should collect.⁴⁶

Interviews were conducted between 2018 and 2019, covering a different time period than the routinely collected data (2014–2017). This means that data extracts from interviews may not directly explain the fluctuations observed within the routinely collected data. However, consultations were arranged with the Willow Team to confirm reasons behind the fluctuations and many of the interviewed HCPs were employed by the Willow Team while the routine data were collected. Therefore, these data extracts are still representative of the contexts surrounding cancer rehabilitation.

This realist-informed evaluation is part of a wider body of work, so not all CMO configurations could be presented here.⁴⁸ Moreover, as this study was conducted prior to the COVID-19 pandemic, it may not be representative of current service provisions. However, based on the 2021 WCPES results, support for PABC did not improve,¹⁵ and the COVID-19 pandemic had a significant impact on cancer rehabilitation services, further highlighting the need to address the inhibiting contexts identified in this study.

Implications for practice and future research

Promotion of cancer rehabilitation is essential and education for the wider MDT needs to be provided to increase staff’s knowledge for improved referral rates and service uptake. Future research could focus on the development, feasibility, effectiveness and implementation of educational and promotional interventions for cancer rehabilitation. Additionally, as the findings suggest that the lack of routine provision of cancer rehabilitation is an inhibiting context, it is important to consider integrating cancer rehabilitation into the treatment pathway. Recommendations from the international literature suggest that conducting a rehabilitation needs assessment from diagnosis through to recovery, or adopting a prospective surveillance model, could help integrate rehabilitation and facilitate the timely identification and management of long-term and late effects of cancer treatments.^{65 66} This continuous surveillance and rehabilitation service integration could be supported by the routine use of patient-reported outcome measures and improved electronic healthcare systems.^{65 67 68} Moreover, embedding rehabilitation professionals or a rehabilitation navigator within cancer centres and care teams can provide PABC with earlier access to the right supportive services.⁶⁹ However, more research is required to test the effectiveness and implementation of new integrated care models, as well as to establish robust evaluations and feedback mechanisms to rapidly improve care provision.⁷⁰



Based on realist philosophy, the stratified nature of reality means that final knowledge cannot be fully achieved, and new contexts and explanations may continue to emerge. In this study, only PABC who completed rehabilitation episodes with either the Willow or Fern Teams were interviewed. However, interviewing PABC who did not receive any cancer rehabilitation interventions from these teams, or who disengaged for any reason, could expand the knowledge base on the factors influencing cancer rehabilitation service uptake. Future research could focus on exploring the experiences and perspectives of PABC who have not received rehabilitation or supportive care.

As for this study, only oncology specialist AHPs working in cancer rehabilitation were interviewed, future research could explore the perspectives of the wider MDT, which could help further develop the CMO configuration presented.

CONCLUSIONS

While cancer rehabilitation has been found to improve clinical and patient-reported outcomes throughout the years, the findings of this realist-informed mixed-methods study indicate issues with cancer rehabilitation uptake due to variations in how PABC were informed about existing services. Information provision was influenced by several contexts, including a lack of consensus on the meaning of cancer rehabilitation, the wider MDT's perception and knowledge on cancer rehabilitation, the prevailing medical model in healthcare and the absence of routine service provision. To address these inhibiting contexts, educating the wider MDT regarding the aim, modalities and importance of cancer rehabilitation is crucial.

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Supplementary material 1 – Interview guides

Patient Interview guide

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?	<p>Could you tell me how you learnt about cancer rehabilitation?</p> <p>What did you think cancer rehabilitation was when you started it?</p> <p>Could you tell me what cancer rehabilitation means for you now?</p>
What are the barriers and facilitators of cancer rehabilitation?	<p>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?</p> <p>Could you tell me what bothered you related to</p>

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<p>What are the barriers and facilitators of cancer rehabilitation?</p>	<p>your health?</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"> • What do you think which aspects of care was helpful (eg. patient information, contact with professionals, exercise)? • Could you tell me in what way was it helpful (eg. getting fit, help with independence)? • How did the care provided live up to your expectations? • Who provided help? • How did you get in contact with them? • Was there anything that made it hard for you to access help or get in contact with a professional? • Could you tell me what made it hard for you to access the cancer rehabilitation service? <p>Do you think this help was enough to ease the problem?</p> <ul style="list-style-type: none"> • What more do you think could be done (eg. more information, more sessions)? • What do you think, why you did not get enough help? <p>After rehabilitation what bothers you about your health condition?</p>
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Supplementary material 1 – Interview guides

What value cancer rehabilitation has from patients' and service providers' perspective?	How did cancer rehabilitation affect your life, everyday activities? What kind of permanent changes the intervention you received evoke in your lifestyle? What do you think in what way cancer rehabilitation was valuable for you?

Supplementary material 1 – Interview guides

Service provider Interview guide

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?	<p>Could you explain to me what cancer rehabilitation means for you?</p> <p>Could you tell me what your expectations of cancer rehabilitation are as a professional?</p>
What are the barriers and facilitators of cancer rehabilitation?	<p>Could you tell me what therapies or support do you offer at your institution?</p> <p>What principles, theories or guidelines do you follow in the therapies and support of cancer patients? Could you explain it to me why?</p>

Supplementary material 1 – Interview guides

<p>What are the barriers and facilitators of cancer rehabilitation?</p>	<p>What are the most common referral routes (eg. consultant, General Practitioner, self-referral)?</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"> • Why do you use this type of patient assessment? <p>Could you tell me what the difficulties you have to face in providing patient care are?</p> <ul style="list-style-type: none"> • What do you think the sources of these difficulties are? • Could you tell me about any institutional difficulties you have to face? • Could you tell me about any patient related difficulties you have to face? <p>What do you think about the 4 level model of rehabilitation?</p> <ul style="list-style-type: none"> • Do you think your work is guided by this model?
<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>

Supplementary material 1 – Interview guides

	What do you think what aspects of health and well-being the support you provide can affect?
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