

“Not another leaflet please”: Improving the delivery of physical activity information and interventions for people with breast cancer

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<p>To Cite: Cowan-Dickie S, Sandsund C, Hunter H, Tigue R, Harris N, Adomah S, Mcleod H, Moore C, Woods M, Corsini L, Doyle N, Wiseman T. “Not another leaflet please”: Improving the delivery of physical activity information and interventions for people with breast cancer. <i>JHD</i>. 2020;5(2):262–275. https://doi.org/10.21853/JHD.2020.100</p> <p>Corresponding Author: Siobhan Cowan-Dickie The Royal Marsden NHS Foundation Trust London, UK siobhan.cowan-dickie@rmh.nhs.uk</p> <p>Copyright: © 2020 The Authors. Published by Archetype Health Pty Ltd. This is an open access article under the CC BY-NC-ND 4.0 license.</p>	<p>SUMMARY</p> <p>This experience-based co-design (EBCD) project integrated knowledge about the physical activity (PA) that positively impacts morbidity and mortality for people with breast cancer with the experiences of delivering or receiving those services.</p> <p>The project identified areas of unmet need for both staff and patients. We prioritised four areas for PA service improvement:</p> <ul style="list-style-type: none"> • Messaging about PA from healthcare professionals • Timing of messaging • Individualising information • Peer discussion <p>The EBCD approach facilitated staff-patient collaboration in re-designing aspects of the delivery of physical activity information and services across the treatment pathway. The proposed improvements are being further developed in clinical practice.</p> <p>Key Words Experience-based co-design; breast cancer; physical activity; rehabilitation and supportive care; patient experience</p>
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ABSTRACT

Emerging evidence indicates that people with breast cancer who engage in physical activity (PA) have reduced morbidity and early mortality. These data motivated a reassessment of service delivery across the treatment pathway. We used an experience-based co-design approach to explore the experiences of the individuals receiving and the people delivering PA information and interventions at a UK cancer centre. Staff and patient interviews revealed that current services were not being delivered equitably and were often not supporting people to achieve therapeutic levels of PA confidently. These findings created a shared sense of purpose and momentum in the co-design of tailored physical activity information and interventions with opportunities for peer support.

BACKGROUND

In 2016, the United Kingdom (UK) reported 55,222 new cases of breast cancer.¹ Breast cancer is the most common cancer diagnosis in the UK. The five-year survival rate is 87 per cent, and the 10-year survival rate is 78 per cent. Maddams *et al* project these numbers to rise significantly as treatments improve, impacting the delivery of health services within the current models of care.²

The American Council of Sports Medicine (ACSM) recommends 150 minutes of moderate to vigorous cardiovascular activity and two strengthening sessions per week.³ Being physically active to the levels recommended by the ACSM is safe and has benefits for people living with and beyond cancer.³ Benefits include maintaining levels of function, wellbeing, and quality of life, and mitigating the effects of cancer treatment.³ Those who are physically active following breast cancer reduce their risk of all-cause mortality (including other long-term conditions, such as heart disease and diabetes) and of breast cancer-related death.⁴ When comparing those most active to those least active, breast, colorectal, and prostate cancer studies⁵ suggest the risk of cancer-specific mortality was reduced by 37 per cent.

Despite this evidence, PA levels remain low in people treated for cancer.⁶ The reasons for this are multifactorial, but one is the lack of messaging about PA by healthcare professionals (HCPs). Schmitz *et al* recently recommended that all oncology clinicians should assess current physical activity regularly, give basic advice on current and desired level of physical activity, and explain that movement matters.⁷ Furthermore, patients should be referred to professionals who can prescribe exercise.⁷ This is consistent with Public Health England guidance that all HCPs should incorporate brief advice and conversations about PA into routine care.⁸ Feedback from HCPs and people treated at our cancer centre suggested that our services were not achieving this aim.

To explore current service and to design a new model that meets patients' needs, we used an experienced-based co-design (EBCD) approach. EBCD was developed and described by Bate and Robert for use in healthcare services.^{9,10} It is an effective service improvement tool and a participatory action research method that has been used in cancer and palliative care services.¹¹⁻¹³ The approach uses a range of methods (eg, observation of the setting, filming of patient stories, and interviews with staff) that place the patient experience at the centre of the inquiry while seeking to understand the setting and staff experience. The filming component with patients deepens the understanding for all participants by identifying and highlighting the "touch points"—that is, the memorable good or bad moments within the current service and helps in the understanding of the context in which care operates.⁹⁻¹³

Together, staff and patients identify key aspects that will lead to service improvements and solutions for the problematic aspects of the current services. EBCD on the approaches of co-production and co-design, which have been used for decades in public services, by introducing these additional elements to experienced-based design.¹⁰⁻¹⁴

The co-design approach of forming groups of patients and HCPs collaborating as equals in addressing distinct identified areas for improvement, keeps the project focused. The physical presence of patients within the groups also serves as a reminder of the imperative to make any changes meaningful and beneficial. This project had two principle aims:

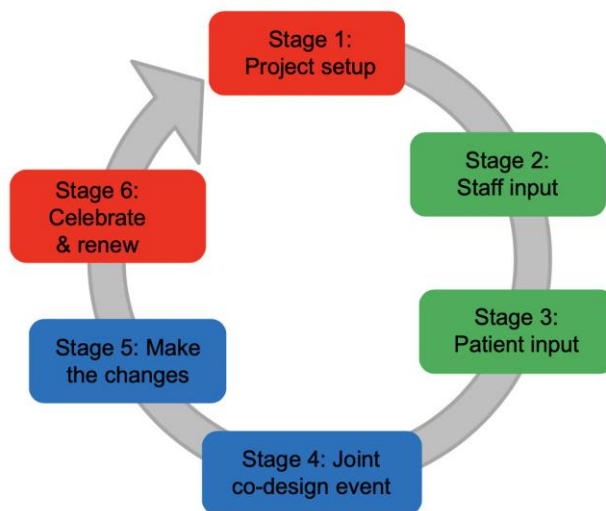
1. To understand the experience of those giving and those receiving the service that promotes PA following breast cancer treatment.
2. To engage staff and patients in identifying priorities and in co-designing service improvements so that people with breast cancer receive support in achieving the recommended/therapeutic levels of PA.

METHOD

Stage 1: Project setup

We used a modified EBCD approach based on the Point of Care Foundation toolkit¹⁴ (Figure 1). A stakeholder group, including senior management and representative staff, supported the execution of the project. We used existing staff resources, and financial support for patient travel and refreshments. The Cancer Centres' Committee for Clinical Research approved the project in March 2018 (SE710). External ethics approvals were not required.

Figure 1: Overview of the six stages of an EBCD project (based on Bate and Robert^{9,10})



Stage 2: Recruitment and gathering staff experiences through observations and focus group interviews

We purposively selected staff to represent clinical, managerial, and administrative groups across a range of pay grades. We recruited them via email and invited them to take part in one of three semi-structured focus groups, facilitated and audio-recorded using a topic schedule (Table 2). We undertook nonparticipatory observation in the clinical and waiting areas of the hospital. The focus group approach is unusual in EBCD methodology, but we used it to make most efficient use of available resources.

Stage 3: Recruitment and gathering patient experiences through focus group and telephone interviews

We approached participants purposively with the aim of recruiting a diverse and representative cohort. We identified them from hospital-run groups and outpatient appointments where PA was discussed. A poster was also displayed at the therapies reception. The eligibility criteria for participants are outlined (Table 1).

After potential participants received a patient information sheet, we attempted to maximise uptake with a follow-up telephone call to facilitate participation. We obtained written, informed consent to take part in all stages of the project. The patient experience-gathering stages included

video-recorded focus group interviews and recorded telephone interviews, both facilitated using the semi-structured topic schedule (Table 2).

After Stages 2 and 3 we collated and examined the data using framework analysis. We identified qualitative themes (touch points) based on the staff and patient focus groups. We compiled a “trigger film” from the patient experiences and used it to illustrate the themes of good and bad moments of care delivery relevant to the topic.

Fifteen patient participants attended focus groups and one requested a phone interview. At the focus group stage, the investigators identified that people with metastatic disease were not represented, so at the co-design stage, they sought opinions from two patients living with metastatic disease who had shown interest in the project after initial recruitment. Their opinions were shared via email. There were 18 participants overall (Table 3). Staff from various professional groups participated (Table 4).

Stage 4: Joint event

Participants at the Joint Event viewed the observational data, the themes arising from the staff interviews, and the trigger film highlighting the touch points experienced by patients. A facilitator arranged participants into multi-interest small groups formed to stimulate discussions about the impacts of the touch points along the pathway, the context of the setting, and the themes from the staff interviews. We facilitated a group discussion to list the identified priorities for improving the service. Based on the group discussions, participants voted on their joint priorities for improvements and selected four issues by vote for the co-design phase. Participants volunteered to join co-design working groups.

Stage 5: Co-design working groups

The self-selected “co-design working groups” of patients and staff met to examine each of the four priority areas in more depth. Each group explored potential solutions to improve the staff and patient experience in relation to the delivery of PA information and services. Group participants explored overlapping and new perspectives that emerged during the discussions and proposed solutions for testing in practice.

Stage 6: Celebration event

We invited all participants and stakeholders to a Celebration Event to hear a summary presentation of the project and to celebrate successes. Participants proposed ideas for further service improvement. Everyone had an opportunity to discuss the project outcomes and the future work.

RESULTS

The main findings showed that although the services promoting PA supported some patients well, there was unwarranted variation. Participants felt that being offered PA support had more to do with “chance” than any systematic procedures. Staff relied too much on generic written information that patients often perceived as poorly timed. We found inconsistencies and lack of clarity in PA messaging given by different HCPs. The opportunity to discuss any PA information in a peer setting was lacking. Most patient participants reported that this absence contributed to

their lacking the confidence to undertake PA independently outside the hospital setting. Participants expressed concern that instructors had limited training and experience in working with people with cancer. Based on these findings, participants selected four priorities for the co-design working groups:

1. PA message delivery
2. Timing
3. Personalisation
4. Peer support

Staff and patient groups identified several qualitative themes (touch points) identified by staff and patient groups (Tables 5 and 6, respectively).

DISCUSSION

The process

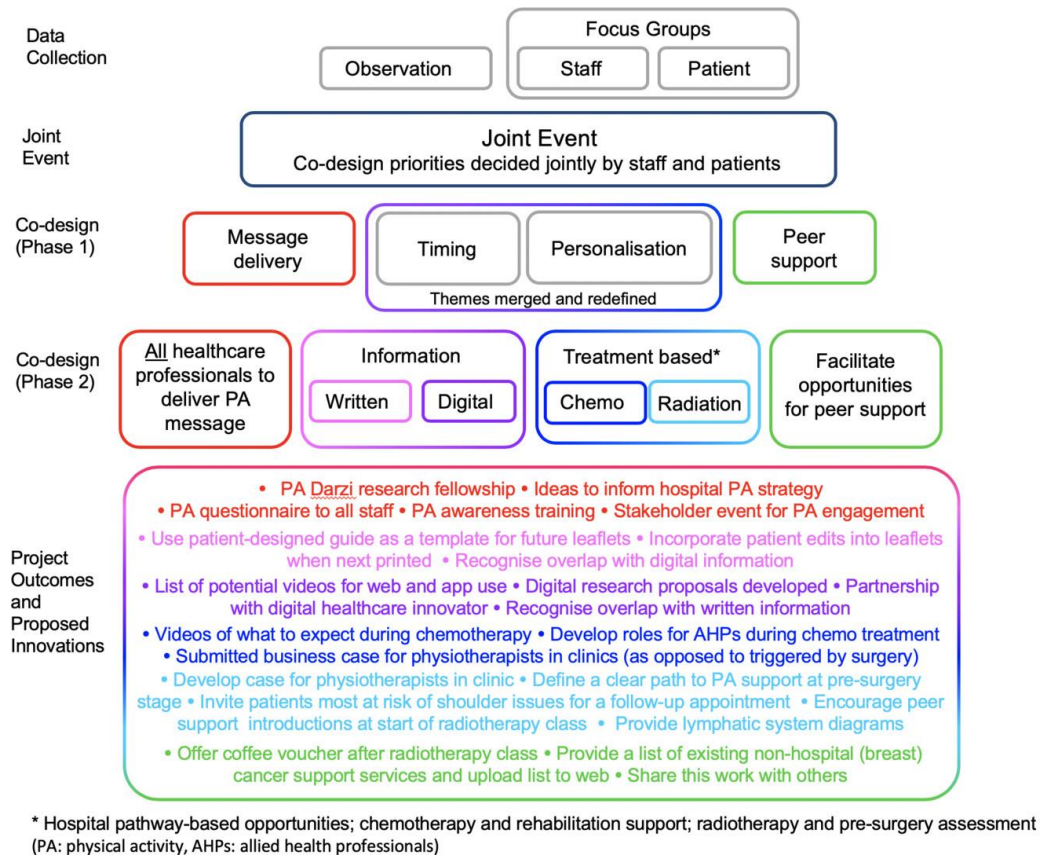
EBCD was a resource-intensive process, but provided the necessary depth of inquiry, reflection, and understanding of the issues surrounding the PA services (Figure 2). Engaging a wide range of staff views, including senior hospital managers and administrative support workers, raised awareness and identified the issues that negatively impact the staff and patient experience. The involvement of senior managers has facilitated the testing of improvements across the treatment pathway.

Observations in clinical areas, waiting areas, and treatment areas allowed the investigators to view the patient journey and the environment to see what messages were visible regarding PA. The investigators found that the environment and treatment pathway did not provide clear messaging, which was consistent with the focus group findings.

Identifying areas for service improvement

The staff findings highlighted that some HCPs did not feel confident in delivering information about PA. Staff acknowledged that resources are finite and that inequalities in service delivery exist, with the harder-to-reach patient groups (eg, language barriers, distance from hospital, time constraints for patients to access, misconceptions about what the services might achieve for them) having similar, if not more, support needs. The patient focus groups and interviews, meanwhile, helped identify where and how PA conversations currently occur, and revealed service areas where service improvements could be made.

Figure 2: Project development, co-design priorities, and outcomes schematic



The trigger film presented during the Joint Event was well received. It effectively contextualised the existing PA experiences from the patient’s perspective, condensing the narrative into manageable bite-sized subject areas for the multi-interest small group discussions that followed. Likewise, the summarised staff findings allowed the small group discussions to proceed with focus and clarity. As the Joint Event progressed, the key issues were taken forward for further consideration. Investigators asked participants to vote on these identified issues to select four priorities (Table 7) to take forward to the co-design groups, the next stage of the EBCD process.

Co-design outcomes

The four areas for improvement (message delivery, timing, personalisation, and peer support) provided opportunity to focus the PA conversation across the whole treatment pathway. The four areas reflect that everyone is an individual with specific concerns, challenges, interests, and knowledge, and therefore, a one-size fits all model is unlikely to succeed. Finally, and perhaps most importantly, participants strongly supported the concept of peer support as an enabler for PA and conversations around exercise.

The small co-design groups examined each priority area in more depth to develop PA service innovations. Participants self-selected into these groups, resulting in roughly equal numbers of staff and patients for each priority, with 7-10 people per group. As these co-design discussions progressed, overlapping and new perspectives emerged. These discussions resulted in a partial redefinition of the priority areas into type of information (written or digital) and the treatment

pathway point (relating to surgery, chemotherapy, or radiotherapy) (Figure 2).

There was a clear message from the patient participants that challenged HCPs to be clearer in their communications with patients about how they could influence their own health from the point of preparing for and while undergoing treatment. They encouraged direct conversations that might be phrased “So this is what we can do for you. Would you like to talk about what you can do to minimise the impact of this?”

Adoption of the latest technologies and digital solutions (eg, videos and personalised training plans) was a solution posed in both staff and patient groups. Digital solutions could potentially engage some harder-to-reach groups and also offer the personalised support. Four patient participants were particularly interested in the option of digital solutions and wanted to be part of future developments. The hospital webpages have been updated with exercise videos and advice on how to eat well to keep fit. We have secured additional grants to expand these digital solutions both on our hospital webpages and via a bespoke platform to develop live and on-demand exercise classes. While the COVID-19 pandemic has expedited the provision of digital solutions, this EBCD work informed the content.

Other simple suggestions included the incorporation of “Please contact me about. . .” tear-off slips into the redesign of any written leaflets to increase awareness of the overall scope of services offered and encourage access the therapy services at a time when needed. We introduced other low-cost, simple-to-implement ideas, including sign-posting patients to existing nonhospital cancer support services and providing a lymphatic system diagram (annotated picture) in the radiotherapy class.

Similarly, recognition that people both learn and explain in different ways will be harnessed by empowering HCPs across the breast cancer treatment pathway to engage in PA conversations with patients. An initial barrier is staff’s lack of confidence in delivering the PA message. A Trust-wide Strategy for Physical Activity has been created that will empower all oncology HCPs to deliver PA messages in line with recommendations in the literature and guidance.^{7,8}

A significant outcome from the project was a successful business case for additional physiotherapy support. A joint physiotherapy, nursing, and dietetic clinic from the point of diagnosis started in February 2020. The findings of this project also helped to inform a predoctoral fellowship for one of the authors to further investigate the use of digital interventions.

Overall, the co-design group members reported that the collaborations have been “productive and creative”, and at the Celebration Event patient participants conveyed high levels of satisfaction with the process and proposed outcomes. The staff and patient participant experiences, co-design group discussions, and project outputs are now informing the development of a PA strategy across our cancer centre.

Limitations of the project

Using focus groups with staff could have affected participants’ ability to speak freely due to the seniority in the groups. However, the investigators elicited diverse opinions across pay grades.

Despite regular project updates, it was challenging to maintain engagement and drive for implementing change to practice among staff with competing priorities.

The number of patient participants is too low to make generalisations, and the initial sampling did not capture people with metastatic disease. The authors sought to address this through email correspondence with two people with metastatic disease. However, including metastatic cancer patients in the focus groups would have allowed more in-depth exploration of their needs and may have influenced the themes.

Investigators chose the purposive method because they wanted to capture people at different stages of the treatment pathway. The investigators attempted to call patients who had been invited to follow up. Reasons for declining to join included not wanting to spend extra time in the hospital or feeling that they didn't have much to add to the project. Another limitation was that the researchers were unsuccessful in gaining funding to backfill clinical time to do the project, which meant they carried out the project alongside clinical commitments.

Future directions

There will be a quality improvement evaluation of the presence of AHPs in patient clinics and work with external digital-health partners will continue. Our concurrent EBCD projects have informed our next AHP Strategy. Continued communication with patients, HCPs, and stakeholders is now central to the delivery of any service improvements.

CONCLUSION

As the evidence that PA reduces morbidity and mortality for people treated for breast cancer continues to advance,⁵ service providers must examine their practices to ensure that patients can access PA opportunities to attain the best clinical outcomes. In using the EBCD approach, we brought together people with breast cancer and their treating staff to identify priorities for service improvements based on a shared understanding of experiences of receiving and delivering timely PA information and interventions. We are developing these new approaches to deliver services that may promote therapeutic levels of PA. We plan to evaluate these new approaches to assess whether they have been well received and have raised our patients' PA levels.

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PEER REVIEW

Not commissioned. Externally peer reviewed.

CONFLICTS OF INTEREST

The authors declare that they have no competing interests.

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ETHICS COMMITTEE APPROVAL

This project was conducted as a service evaluation (CCRSE710) approved by the Royal Marsden NHS Foundation Trust Committee for Clinical Research.

Table 1: Participant eligibility criteria for the EBCD project

<p>Staff Participants Staff involved in any aspect of the service for people with breast cancer, including administrators, clinicians, clinical managers, and senior management.</p> <p>Patient Participants</p> <p><i>Inclusion criteria</i></p> <ul style="list-style-type: none"> • People who are 18 years of age or older and have been treated at the hospital for breast cancer • Those with adequate linguistic and cognitive function to participate in interviews and group discussions • Those who have accessed physical activity advice and information <p><i>Exclusion criteria</i></p> <ul style="list-style-type: none"> • People with insufficient English or capacity to take part in a focus group independently

Table 2: Physical activity topic schedule for stimulating discussion during staff focus groups

<p>PA General Questions</p> <ul style="list-style-type: none"> • What is the overall aim of giving people information or exercises when they have a diagnosis of and treatment for breast cancer? • What is your overall experience of the physiotherapy information you give? Did this achieve your aims? • How does it feel to give the information? • How do you think people are able to take it on at different phases? <p>PA Information Questions</p> <ul style="list-style-type: none"> • What seems to work best when you deliver information to people? • What works least? • What is your view on how the information is presented? • What about the amount of information? • The specific detail of the exercises (eg, the number, the time, the repetition, how hard you should exercise, how often people should exercise?) • What do you think helps or hinders people? <p>PA Follow-up and Sign-posting Questions</p> <ul style="list-style-type: none"> • What do you advise around how people can contact you with queries? Get follow-up appointments? Update the exercise/physical activity as they go through treatment? • What other information and resources do patients/family tell you they get about physical activity/exercise from other HCPs? <p>PA in an Ideal-World Question:</p> <ul style="list-style-type: none"> • If you had a blank sheet of paper to design the physiotherapy information provision about physical activity/specific exercises in a way that worked better for you how would you do it? • Is there something else you would like to mention?

Table 3: Patient age, ethnicity, and range of treatment

Age	N
41-50	3
51-60	6
61-70	7
71-80	1
81+	1
Gender	
Male	1
Female	17
Ethnicity	
White British	12
White Other	2
White Irish	2
Black Caribbean	1
Not disclosed	1
First language	
English	16
Non-English	2
Treatment received	
Surgery	17
Chemotherapy	11
Radiotherapy	8
Hormone therapy	10
Targeted therapy	3

Table 4: Number of staff by professional group

Staff Professional Group	Attendees
AHP-Dietetics*	3
AHP-Occupational Therapy	2
AHP-Physiotherapy	9
AHP-Radiotherapy	5
Lymphoedema	2
Nursing: CNS	1
Nursing: ANP	1
Nursing: Consultant	1
Exercise and Yoga	2
Psychological Care	2
Divisional Director level manager	1
Service level manager	2
Digital and Patient Information	2
* AHP=Allied Health Professional	

Table 5: Qualitative themes or “touch points” identified by staff

Theme	Subthemes
Giving support about physical activity	<ul style="list-style-type: none"> • Unsure what PA information to give • Concern about limited time and opportunity to impart the necessary information to patients <ul style="list-style-type: none"> - Awareness that patients might not be receptive at that time - Knowledge that at a specialist cancer centre other healthcare professionals may not have the competence to answer questions that patients will subsequently have—even if they are not articulating them • Concern that a lack of planned follow-up left staff unsure of the impact on their own intervention has
Resource limitation	<ul style="list-style-type: none"> • Acute awareness of how constraints were limiting the overall quality of the interventions that staff wanted to provide • Desire to be able to adapt interactions in response to need • Wish to develop and offer creative solutions to the issues they see
Inequality of delivery	<ul style="list-style-type: none"> • Awareness of several factors: <ul style="list-style-type: none"> - Service delivery was not equitable or standardized - Some patients are not aware of, nor have access to, the existing services - Access to hospital-based services was not possible for all patients - Patients that are harder to reach having similar, if not more, need

Table 6: Qualitative themes (touch points) identified by patients

Themes	Subthemes
Issues around physical activity	<ul style="list-style-type: none"> • Impact of physical activity on daily activities • Fear and hesitation around unguided progression of activity • Perceived chasm between cancer-specific physical activity information and real world activity opportunities • Distrust of noncancer-trained exercise professionals understanding the needs of those after a cancer diagnosis • Massive disconnect between the post-surgery breast exercises and return to work needs • Workplace Occupational Health provided no guidance; an absence of physical follow-up left patients unable to access professional healthcare (or GP) support for workplace needs
Messaging from healthcare professionals	<ul style="list-style-type: none"> • The impact of tone, quality, and consistency of content in communication, the availability of skilled supportive care, and contact with staff generally made a difference to a patient’s self-efficacy and confidence overall • Casual, unspecific, chance findings or conflicting messages engendered uncertainty around progress and completion of care • The exercise message and physical activity services did not feel part of the overall treatment package
Chance aspect to accessing services	<ul style="list-style-type: none"> • Locating and accessing available rehabilitation therapy services was haphazard, leading to a sense of uncertainty and incompleteness (eg, radiotherapy class, complementary therapies, physical activity services, acupuncture, yoga)—no overview was readily available • Great frustration in finding and accessing appropriate skilled support at time of need.
Reliance on written leaflets	<ul style="list-style-type: none"> • Written information was handed out at times to suit the healthcare professional HCPs • Perception that staff relied on the leaflets with little opportunity for PA discussion • Lack of personalisation and tailoring of the available services left patients feeling that the information is for everyone but no-one • Absence of gender specific information

<p>Opportunities to talk</p>	<ul style="list-style-type: none"> • Reflection on the importance of support to “talk things out”, to make sense of information and to understand it in an oral way • Sense of difficulty to “transition”—to increase the self-care in their lifestyle, to improve their outlooks and futures without the opportunity to think how to make that work in their own reality • Awareness that talking is important and at the hospital people understood the impact of the treatment, but that there was a reticence to offer opportunities to talk • Treatment is an isolating experience, especially if denied access to peer support because of minority status
<p>The value of therapies</p>	<ul style="list-style-type: none"> • Acknowledgement of guilt associated with diagnosis, that lifestyle may have led to cancer and wanted support to work through this • “Therapies” gave a sense of self-care that was valued and could be taken away for use in their own recovery • Hospital-based therapy services felt “safe” and were considered as part of the treatment package • Recognition that these therapies gave them space and time to process what was happening, despite initial feelings of indulgence • After an initial referral, there was a “conduit” to other therapies
<p>The impact of not meeting unmet need</p>	<ul style="list-style-type: none"> • Generally, people reported that the absence of help left them feeling isolated and helpless