

Improving psychological support for people affected by cancer in Portsmouth

2024



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IMPROVING PSYCHOLOGICAL SUPPORT FOR PEOPLE AFFECTED BY CANCER IN PORTSMOUTH.

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Project Leadership	Dr Emily Connolly & David Haylock
Clinical Lead	Dr Andrew Merwood

Purpose of document

- To review, during project closure, how the project progressed compared to the Business plan, project plan, and other project documentation that outlined the aims and scope of the work.
- To share lessons that can be usefully applied to other projects and the passing on of details of unfinished work, ongoing risks or potential product upgrades or modifications to the team that will support it.

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Project aims

The Improving Psychological Support for people affected by cancer in Portsmouth project aimed to:

- Understand the experiences of people affected by cancer who have accessed either Talking Therapies Portsmouth (formerly Talking Change) or the Macmillan Counselling & Psychology Service, and the experiences of the staff that have worked with them.
- Bring staff and people affected by cancer together to reflect on these experiences, identify problems and generate solutions for a pathway of psychological support.

Summary of findings

Key findings

- Staff in both the Macmillan Counselling and Psychology service and Talking Therapies Portsmouth had limited knowledge of each other's services and how they worked with people affected by cancer. This meant that there was no established pathway for referrals between the two services.
- People affected by cancer did not feel that their psychological needs were consistently recognised, understood, or supported from the point of diagnosis onwards, by a range of healthcare professionals.
- People affected by cancer wanted to know where to go when for psychological support, with staff providing a "warm handover" to these services rather than simplistic signposting. It was important to them that staff in any services they were signposted to had a specific understanding about the psychological experience of cancer.
- Talking Therapies staff expressed a range of concerns about working with people affected by cancer and wanted further training and closer working links with specialist services.
- There was a desire from both the Macmillan Counselling and Psychology Service and Talking Therapies Portsmouth to establish closer working links.
- Experience Based Co-Design (EBCD) is a powerful method for hearing and understanding experience of services. It provides a flexible template to involve people in improving the care they receive. EBCD enabled conversations between people affected

by cancer and staff across services, to better understand the problems with existing psychological support and to begin to think about ways of improving these problems.

Key recommendations

- The development of an online place-based Cancer Psychological Support information hub, to contain information about services available, how those services work, referrals processes, how therapy works and in what environments therapy will be offered. This information should include illustrative videos of the services, along with videos of people who have been affected by cancer talking about their experiences of therapy. There will be additional information for carers and professionals.
- The continued development of closer working links between the Macmillan Counselling and Psychology Service and Talking Therapies Portsmouth, including working towards co-facilitating interventions such as therapeutic groups and co-locating individual therapy within the Macmillan Centre.
- The development of a training package for Talking Therapies staff to build their confidence in working with people affected by cancer. This training package should bring together the expertise of psycho-oncology services, cancer healthcare professionals and people affected by cancer.
- Psychological services should promote the role of conversations about the psychological impact of cancer across the cancer pathway. People affected by cancer clearly articulated that psychological support is not solely the role of specific psycho-oncology and Talking Therapies teams. Psychological services should consider how they may upskill the wider healthcare workforce, to normalise, recognise and understand the psychological impact of cancer from diagnosis, through treatment, and beyond.
- When building pathways between specialist psycho-oncology services and Talking Therapies services, time should be taken to build a partnership with each team recognising the other's expertise, remit, and limitations. This enables staff to learn about other services and builds confidence and trust in onwards referrals. All of this supports the goal of “no wrong door” to services, where someone can present at one service, and whereby staff with an understanding of the wider cancer system can complete a “warm handover” to the most appropriate service for that person at that time.

Acknowledgements

We would like to thank the people affected by cancer and staff who support them, who brought this project to life, sharing their experiences, ideas, and commitment to improving psychological care. Our thanks also go to Wessex Cancer Alliance for funding the project, and specifically to Kathy Cook and Stephanie Heath whose guidance got the project started, and Teresa Corbet who helped us finalise this report. We are extremely grateful to the team at the Solent Academy of Research and Improvement, specifically Carl Adams and Natalie Royston for their help and commitment to improvement and participation. We'd also like to thank Charlotte Mills, from Macmillan Cancer Support for supporting us to recognise all those involved in the project. Finally, thank you to the service leads of the Macmillan Counselling & Psychology Service and Talking Therapies Portsmouth, Dr Andrew Merwood and Marina Ulanova who recognised the value of this project and supported us to complete it.

A note on language

In much of the EBCD literature, the terms “patients” and “staff” are used to distinguish between the two different experiences the process seeks to explore. As you read this report, you will see that the term “patient” is used sparingly, primarily when referring to the specifics of the EBCD process or referencing EBCD literature. We know that many people who have had to adopt a patient *role* at some point in their lives, rightly take issue with that role being assumed as the entirety of their identity. Throughout the majority of the report, you will therefore read the term “people affected by cancer”. This term represents the broad range of people whose lives are impacted by a cancer diagnosis. This could be the person who receives the diagnosis, but could equally be a family member, loved one, carer, or friend of someone receiving that news. We distinguish these experiences from those of “staff” (describing those who work within, or closely with the services detailed in the report) to separate the different experiences. We are aware that this is an imperfect distinction, staff will of course be affected by cancer in their work and may also have been affected by cancer as an individual, or a family member themselves.

Background and introduction to the project

The NHS Talking Therapies for Anxiety and Depression programme (formerly known as the Improving Access to Psychological Therapies (IAPT) programme) began in 2008, with the aim of improving the availability and delivery of evidence-based psychological therapies for common mental health difficulties (NHS England, n.d., a) in the community. In 2018, following successful work at early-implementer sites, the programme was expanded to offer psychological therapy for common mental health difficulties associated with a long-term health condition (LTC) (National Collaborating Centre for Mental health, 2018). Guidance from the National Collaborating Centre for Mental Health (2018) outlines that in order to create effective integrated LTC pathways, Talking Therapies services in the community need to be linked to specialist health care teams (including Clinical Health Psychology). This collaboration between services is important to share knowledge, best practice and skills, and to ensure people are seen at the right time, by the right service, for their needs. Pathways now exist for a range of LTCs such as pain, diabetes, and chronic obstructive pulmonary disorder.

Although cancer is classed as an LTC and training is provided within the existing Talking Therapies LTC top-up training pathway (NHS Talking Therapies, 2023), as of December 2022, only 46% of Talking Therapies services had a pathway in place for cancer (Cartwright, 2023).

To meet the psychosocial needs of people affected by cancer, new working relationships and pathways between psychological professionals need to be facilitated. The 2022/2023 Cancer Alliance planning pack (NHS England, 2022) highlighted the importance of promoting Talking Therapies' work with people affected by cancer, to support their improved quality of life. When considering this promotion, Cancer Alliances need to work closely with local Psycho-oncology teams, the highly specialist services whose work focusses on the psychosocial needs of people affected by cancer. These teams are often based in acute hospital settings and offer direct and indirect care to people affected by cancer, as well as supporting the multi-disciplinary teams who deliver cancer care (Transforming Cancer Services Team (TCST), 2020).

The existing capacity of psycho-oncology services to deliver specialist psychological support across the cancer pathway cannot meet demand, with 1 in 4 people affected by

cancer expected to need specialist psychological support in the year following a diagnosis (NICE, 2004). In addition, the psychological impact of cancer is not limited to a set time frame, with 54% of people living beyond cancer still experiencing a mental health difficulty up to 10 years later (TCST, 2020). This longer-term need does not necessarily sit well with psycho-oncology services when people are far less likely to be in regular (if any) contact with acute hospitals and thus less likely to be referred. Work in London by TCST has led to the development of a working model for an integrated cancer psychosocial support pathway (seen in Figure 1), which recognises both Psycho-oncology’s and Talking Therapies’ specialist knowledge.

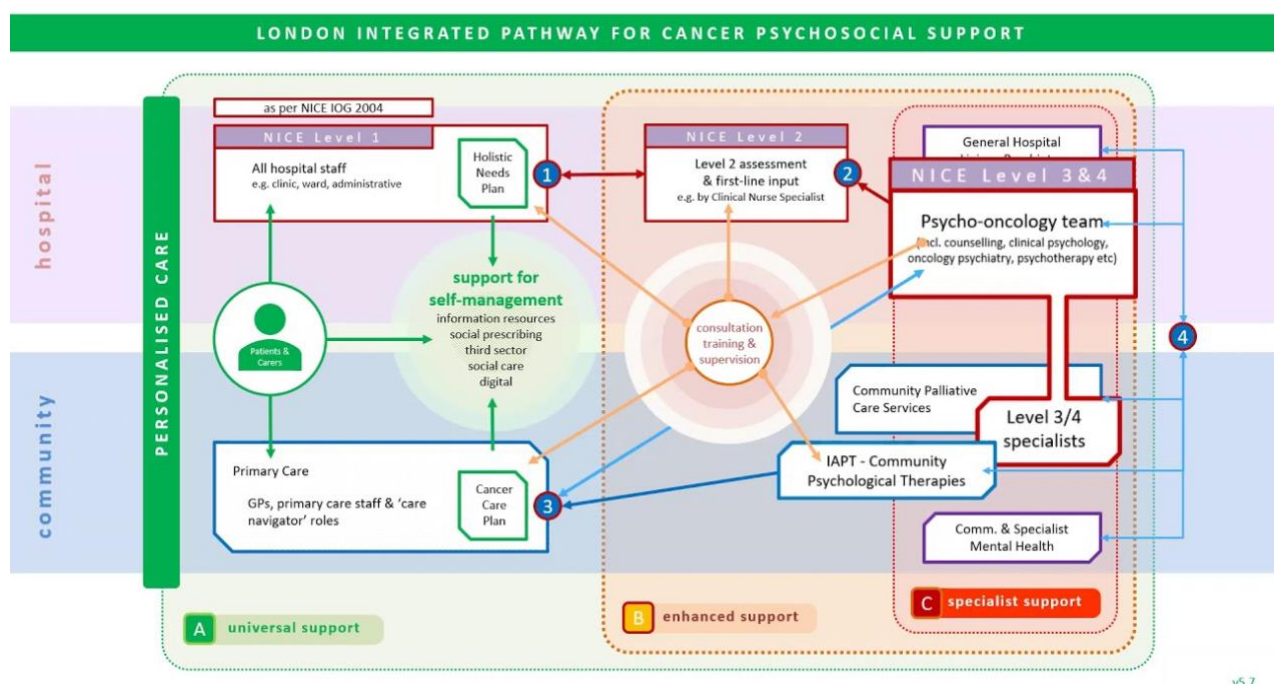


Figure 1. London Model of Integrated Cancer Psychosocial Support Pathways (Transforming Cancer Services Team (TCST), 2020)

The local picture before the project began.

The Macmillan Counselling and Psychology service (MCPS) is a specialist psycho-oncology service based at Queen Alexandra Hospital, Portsmouth Hospitals University NHS Trust. The hospital serves the local population of Portsmouth City and South-East Hampshire, while the Regional Cancer Centre provides specialist cancer services to people affected by cancer from Portsmouth and South-East Hampshire, the Isle of Wight, and parts of West Sussex. MCPS is set up to deliver psychological interventions in line with the levels of care outlined in the NICE (2004) guidance for people affected by cancer. Staff members include

Clinical Psychologists, Trainee Clinical Psychologists and Counsellors. Referrals are made by professionals involved in a person's cancer care, most commonly the person's cancer Clinical Nurse Specialist (CNS). In the year prior to the project starting (2021-2022), 192 people affected by cancer were referred to the service.

Talking Therapies Portsmouth (TTP) is part of the national Talking Therapies for Anxiety and Depression programme (NHS England, n.d.). The service is based in the community and provides support for those living in Portsmouth City (postcodes PO1-PO6). Interventions are offered in a range of formats from in person face-to-face appointments at the city centre base, as well as online via video communication platforms, and over the telephone. The team consists of a broad range of psychological professionals who offer a range of psychological therapies. In the year prior to the project starting (2021-2022), TTP had been accessed by 48 people affected by cancer.

Prior to the project's inception, there were no clearly defined pathways between MCPS and TTP. MCPS staff had signposted and referred to TTP occasionally, but no one in TTP had ever made a referral to MCPS. Contact between the teams was limited, often relying on clinicians knowing one other staff member. No feedback had been sought or received following a referral, so staff did not know how helpful an intervention may or may not have been.

Initial project plan and scoping work

As part of the initial scoping work, advice was sought from other psycho-oncology services who had established pathways with Talking Therapies teams. Recommendations included piloting the pathway with one speciality initially, prior to roll out across all cancer groups. The Senior Clinical Psychologist carried out an audit of MCPS referrals over the previous 12 months, to explore potential pilot specialities. The highest proportion of referrals into MCPS in 2022 came from the Breast care team, with 38 referrals made, accounting for 23% of total referrals. Each of the 38 referrals were then screened using the referral criteria detailed in the London Psychosocial Pathway business case (TCST, 2020). Of the 38 referrals, only 4 were potentially suitable for an onwards referral to Talking Therapies services. This scoping work highlighted several key considerations, outlined in Figure 2:

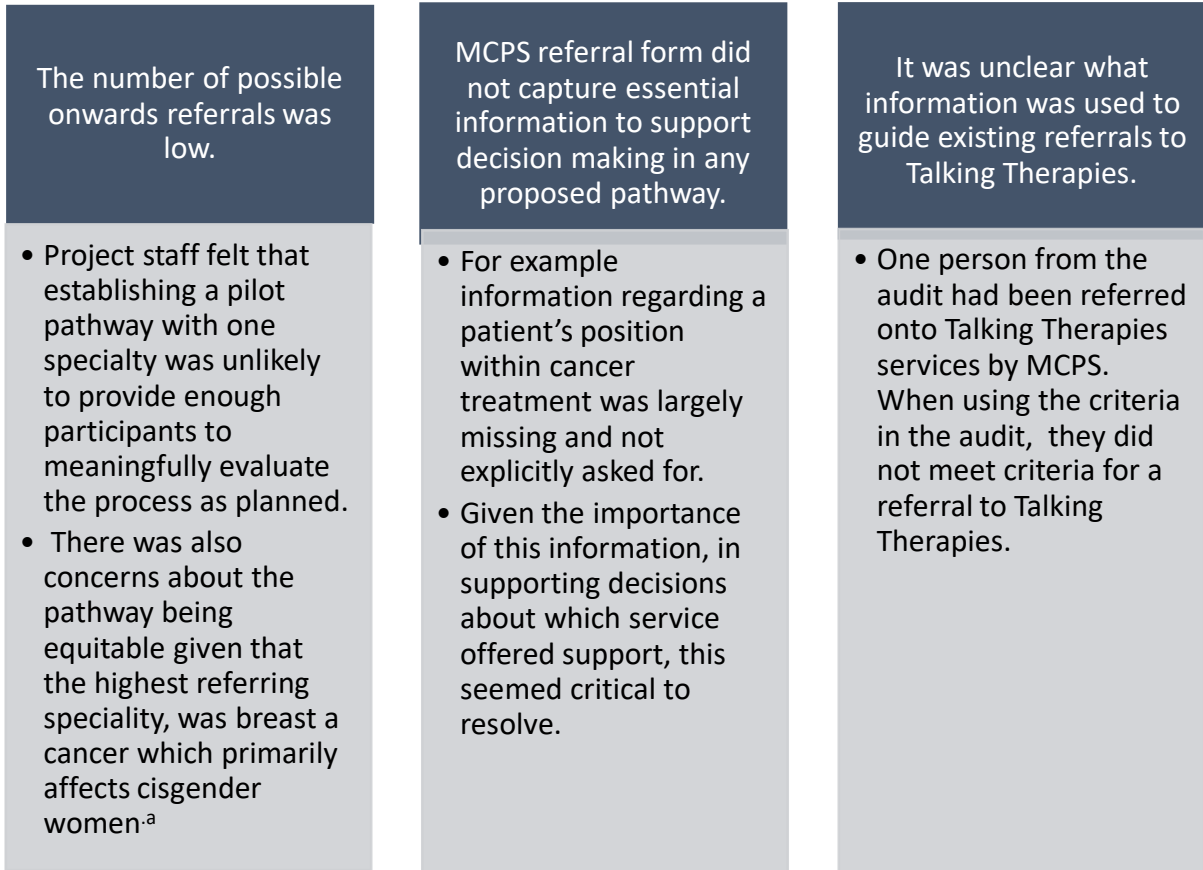


Figure 2. Key considerations from scoping work:

^aThe lifetime risk of breast cancer is higher in cisgender women, than in cisgender men (Sonnenblick et al, 2018). There is limited evidence to understand the risk within trans women and trans men, but one study has shown that trans women have a higher risk profile than cisgender men (De Blok et al, 2019).

Alongside the initial scoping work carried out, members of the project team also attended Experience-Based Co-Design (EBCD) training. Following attendance at the training, the project team realised that in asking people affected by cancer and staff to evaluate a pre-designed pathway, they missed the opportunity of co-designing it from the start. As early conversations continued between MCPS and TTP, it also became clear that staff in both services knew very little about the other. The project team felt that using EBCD presented an opportunity to understand more about the current experiences of people affected by cancer

and staff, to learn more about each service in the process, as well as promoting more meaningful involvement in the pathway for both groups. Therefore, rather than using EBCD once a pathway was in place, the team agreed to use it as a tool to create a pathway from the outset.

Project plan

The project was supported by a successful bid to the 2022/23 Wessex Cancer Alliance (WCA) Workforce Transformation fund, the purpose of which was to *“support the development and sustainability of locally designed oncology projects that address workforce transformation challenges.”* The funding paid for a 0.6 WTE band 8A Senior Clinical Psychologist’s time on the project, and also enabled the project co-leads and MCPS Service Lead to attend EBCD training.

Method

EBCD is a quality improvement method used to bring patients and staff together to identify problems with services and/or pathways, and to co-design solutions (The Point of Care Foundation, n.d., a). EBCD has been adapted within healthcare settings, to varying different timeframes, budget requirements and problems (Green et al, 2020). The stages of EBCD are detailed in Figure 3.

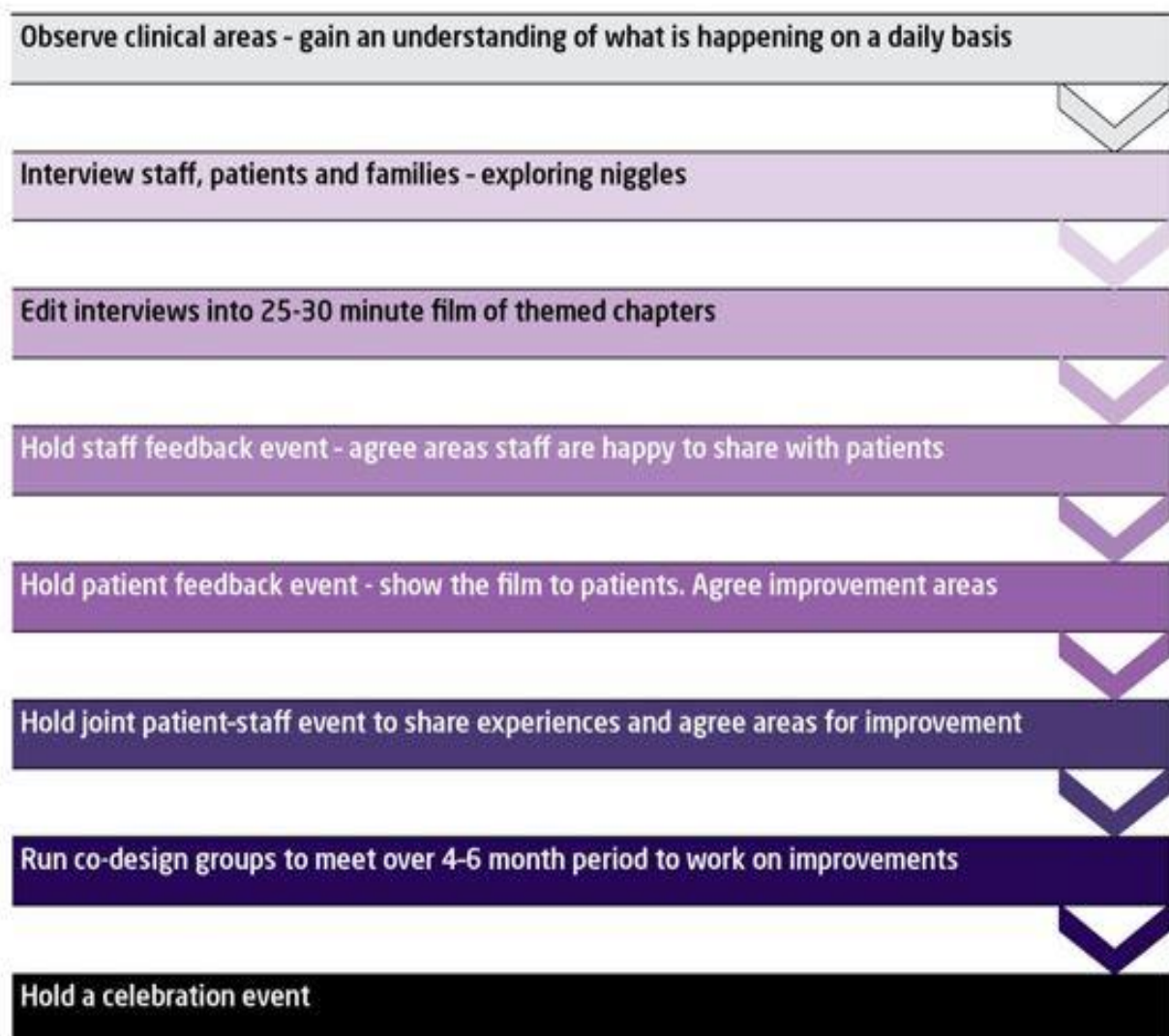


Figure 3. Stages in Experience based co-design (The Point of Care Foundation, n.d., a)

Prior to the study: Observing clinical areas

Part of the EBCD process outlines the importance of experiencing the setting/service from an observer perspective. The idea of doing so is to immerse yourself in the experience, allowing it to be seen with a fresh pair of eyes (The Point of Care Foundation, n.d., b). For this project, a staff member from each team observed the other service to understand what someone affected by cancer may experience.

One TTP staff member attended in person a weekly MCPS triage meeting where referrals are discussed. They also spent time observing the environment, visiting the Macmillan Centre where the counselling room is based, and the psychological therapy room based in an oncology ward.

To observe TTP, pictures were taken of the entrance, waiting room and therapy rooms of the TTP base. Informal conversations were held with TTP staff members including team administrators, staff who conducted triage assessments, and those who delivered psychological therapy. Given the ability to self-refer into TTP, time was also taken to explore a “possible route” to referral by spending time reviewing the TTP website to understand this experience.

Across both services, time was taken to understand the processes someone would go through when accessing the service, including the referral and the information they may receive (e.g. letters/phone calls).

Recruitment and Engagement: Involving people affected by cancer and staff.

The project team sought to recruit people affected by cancer who had accessed either MCPS and/or TTP. In order to learn from as many experiences as possible, those who had accessed TTP were invited to take part even if cancer had not been the main focus of their work with TTP.

For the initial interview stage, TTP staff who had worked with someone affected by cancer were invited to take part, including when cancer had not been the main focus of this work. For the later improving experience phase, all TTP members of staff were invited. All MCPS staff were invited to take part in all stages. Given the small numbers of staff within the MCPS team and the likely impact of an improved psychological pathway on their work, CNS colleagues were also invited to share their experiences of working with MCPS.

The project team used a number of methods to recruit people for the project as seen in Figure 4.

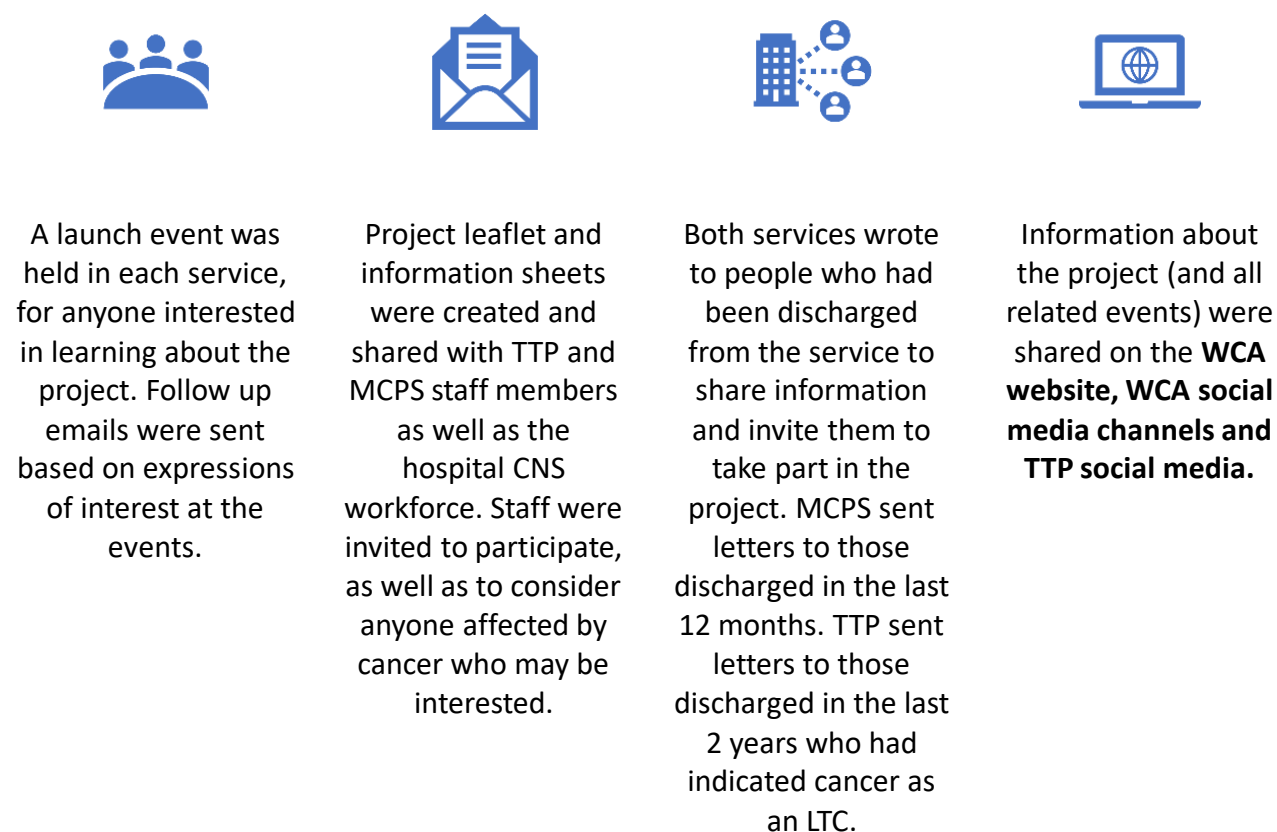


Figure 4: Project recruitment methods

It was anticipated that due to the lengthy time period of EBCD (up to 7 months), that there would be a turnover of participants. The project team made clear to all participants, that their contribution was valued no matter the duration of their involvement. Participants were made aware that they did not need to commit to both the capturing and improving experience phases.

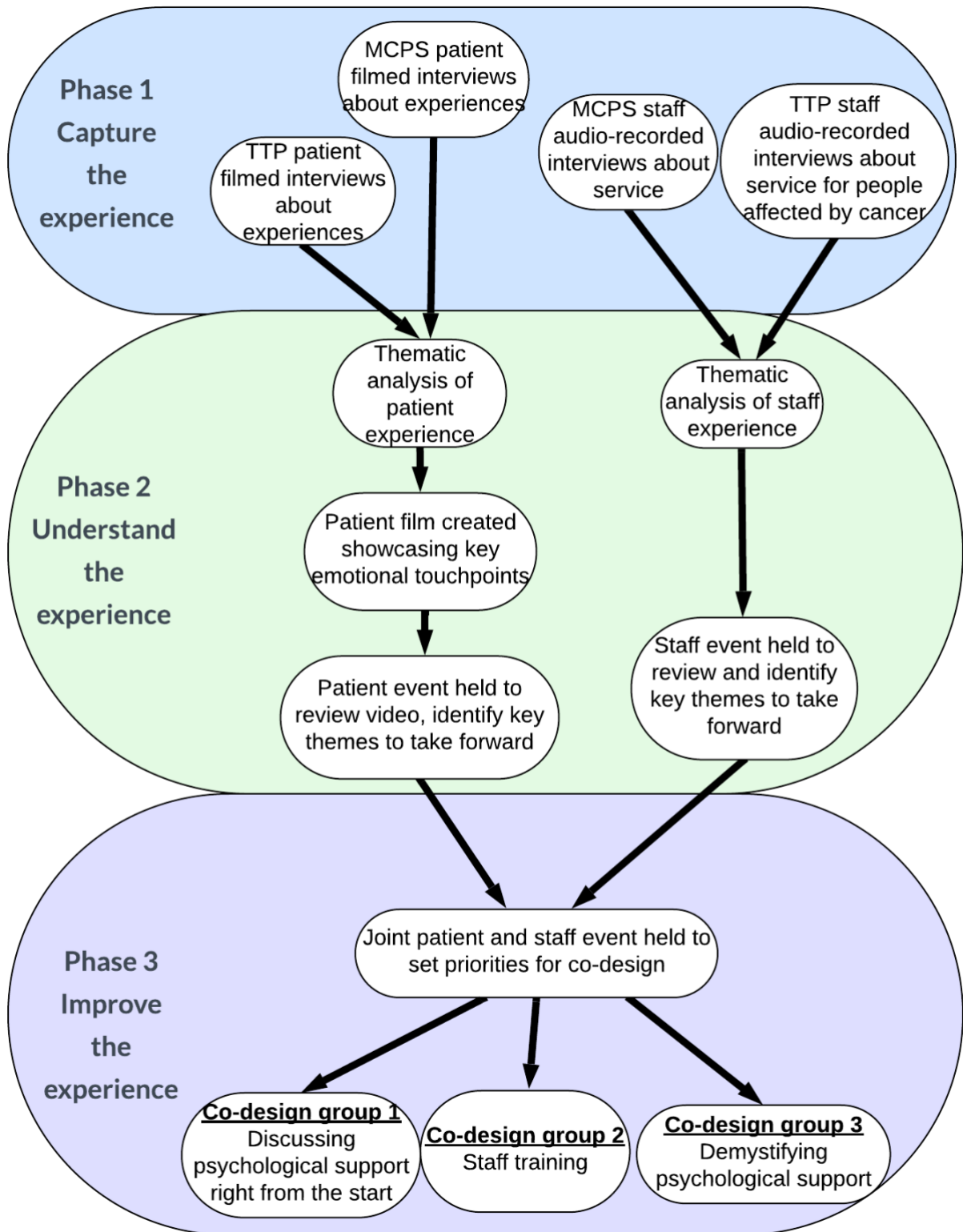


Figure 5. Study design (diagram adapted from Twamley, Monks & Beaver, 2023)

Phase 1: Capture the experience

As shown in Figure 5, interviews for both people affected by cancer, and members of staff were conducted to capture experiences of psychological services. For people affected by cancer, interviews took place either remotely via Microsoft Teams, or in person in the hospital medical photography department and were recorded. Recordings were for the most part, video and audio record with the exception of one audio only recording. In interviews, people were asked about their experience with either MCPS or TTP. An opening question of “*What were your first thoughts about accessing psychological support?*” was asked, which allowed the person to begin their narrative at a place they felt was most fitting. Interviewers followed an interview guide (Appendix A), which covered key points of a typical “journey” through healthcare¹: a referral, initial assessment, psychological therapy itself and ending psychological therapy.

The interview guide contained some different questions for those accessing either service, in recognition that cancer may not have been their primary reason for accessing TTP. People affected by cancer were all also asked about their ideas for a psychological support pathway, whether they knew about both services, and how better links could be created between MCPS and TTP. The interviews were relaxed and conversational in style, allowing people to naturally tell their story with interviewers responding to emotion, and key points raised. Those interviewed had accessed a range of different levels of psychological interventions in either service with some having previous experience of both services. A total of 11 people affected by cancer were interviewed as part of the project, 6 from MCPS and 5 from TTP.

Staff interviews were conducted either remotely via Microsoft teams or in person. They were audio recorded and transcribed. Again, the interviewers took a flexible, conversational approach to the interviews and interview guides were tailored to specific staff groups (e.g. MCPS/Wider MCPS workforce (CNS)/TTP – see Appendix B and C). Staff interviews took place with 6 staff from MCPS, 2 CNS from the wider MCPS workforce, and 5 TTP staff.

¹ The depiction of someone’s cancer experience using the metaphor of a “journey”, is now more commonly used by healthcare professionals than historically used violence based metaphors (e.g. “battle with cancer”). Semino E, Demjén Z, Demmen J, et al. (2017). The online use of Violence and Journey metaphors by patients with cancer, as compared with health professionals: a mixed methods study. *BMJ Supportive & Palliative Care*, 7, <https://doi:10.1136/bmjspcare-2014-000785>.

Phase 2: Understand the experience

Following the recording of all participant interviews, thematic analysis was conducted. As shown in Figure 5, initially themes were created individually, and then combined to create an overall set of themes for each group of people. A 30-minute catalyst film which captured the overall themes from people affected by cancer was then created. Within EBCD, the catalyst film of key themes is created to provide an opportunity for patients to convey their experiences and emotions firsthand to staff, as well as to foster empathy and provoke conversations at later stages of the process (Donetto et al, 2014). This film was edited and created by the Medical Photography team at Portsmouth Hospitals University NHS Trust. People affected by cancer had the opportunity to review their own video to approve the inclusion of key clips, as well as to collectively view the overall film at the patient only event. At this event, people were invited to share their thoughts on the overall themes developed during analysis, and to identify the key themes that as a group they felt were the most important to take forward to the improvement phase. Staff interviewed also reviewed their collective themes, at the staff only event as well as identifying their priority themes to take forward.

Phase 3: Improve the experience

A joint event for people affected by cancer and staff was then held to review the themes brought forward from the understanding experience phase. Themes were discussed, elaborated, and explored before votes were cast as to the key priorities for the co-design phase. Three themes were chosen to take forward to co-design groups which can be seen in Figure 5.

Each co-design group met for 6 hours, over a period of 6 weeks. To maximise attendance at the groups, they were held in a hybrid format (in person at the Macmillan Centre and via Teams) and matched to people's availability where possible. This meant that some groups met weekly, and others met less frequently for a greater duration of time. When planning the groups, project leads tried to include a mixture of people affected by cancer, TTP staff, and MCPS staff across each theme. The groups were facilitated by the project leads. The co-design meetings consisted of exercises which encouraged exploration of possible solutions, considering impact of these solutions, before moving towards making plans to improve the problems.

Within the co-design phase, hopes of regular attendance were encouraged with a recognition that people may attend intermittently. The project team continued to promote the project for its entirety, resulting in other participants joining following the initial capture phase. This meant that following the initial 22 participants interviewed, an additional 8 staff members, and 3 people affected by cancer took part in co-design.

Findings from Phase 1 and 2: Capturing and Understanding the experience

Key findings from service observations

In observing the environments from a different perspective, staff noticed several important areas for improvement. From a TTP perspective, there was no information available about cancer in their physical or online environment. Within their waiting room, there was no information about working with cancer, or any cancer related posters. On their website, no reference was made to cancer as an LTC that staff were trained to work with. This was a surprising discovery and demonstrated how staff are not always aware of the information that is available about services. The project team felt that this could impact people affected by cancer, as they may not be aware that TTP can work with their specific difficulties.

Similarly, MCPS observations highlighted potential problems with the therapeutic environment. The psychological therapy room in the oncology ward was not well signposted and often there was no member of staff in the reception area to direct people to the therapy room. The project team discussed how the location on the ward was already quite a clinical setting, and wondered how the lack of welcome by a member of staff may leave people attending therapy feeling.

Key findings from interviews

The interviews with people affected by cancer and staff generated a rich, and extensive set of learnings with both services taking away improvement ideas for their individual services, and to support their closer working within any pathway developed. The key themes from both sets of interviews can be seen in Figure 6.

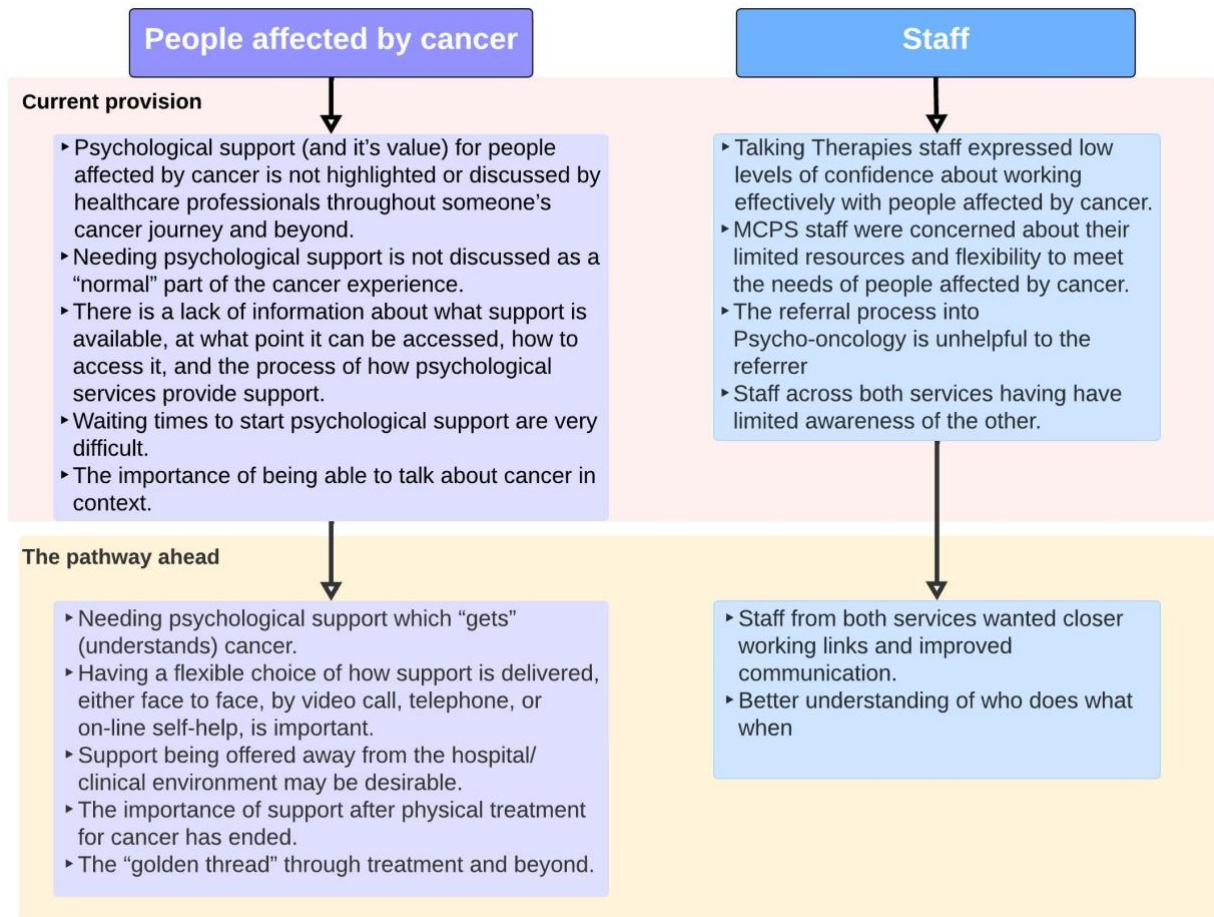


Figure 6: Key themes from interviews with people affected by cancer and staff regarding current provision and the pathway ahead.

Key themes from people affected by cancer – Current provision

Psychological support (and its value) for people affected by cancer is not highlighted or discussed by healthcare professionals throughout someone's cancer journey and beyond.

"All these years, no one has ever said to me, "Did you know that you can access really good psychological support, specifically for people who've been through what you've been through, through TTP?" No one ever says "This would be really good for you. This will really help you.""

People affected by cancer reflected on experiences across the healthcare system from GP surgeries to oncology appointments where they felt opportunities to discuss the psychological impact of cancer were missed. These experiences ranged from at best, people mentioning available psychological support with little context, to in the worst cases people starting the conversation with professionals who then shut it down:

“I was just testing the water, I remember saying, “People have said when you come to the end of treatment that’s the time it’s challenging for people and probably worth looking for some counselling and something.” And she said, “Oh some people just get on with it. So, you shouldn’t assume that’s what you’re going to need.” I was a bit gobsmacked by that but the clear message I got there was actually we’re expecting you to crack on and not make a nuisance of yourself.”

Needing psychological support is not discussed as a “normal” part of the cancer experience. *“It does appear in some of the literature and some of the conversations, but I don’t think it’s normalised. It is there, but there needs to be more of a narrative around it. I think rather than, “Well here’s where you can go if you’re struggling”, it’s more the narrative around how it’s a natural part of that journey.”*

Following on from the previous theme, people affected by cancer felt that when psychological support was discussed it was not treated as an understandable and normal part of the cancer journey. They spoke of the body and mind being treated as separate entities by professionals, in stark contrast to their lived experience.

Some people interviewed had previously accessed psychological therapy prior to cancer. There was a strong sense among people affected by cancer involved in the project, that this had meant they were more active in pursuing it as they had found it beneficial previously. They were acutely aware of other people who may not have had this experience. They felt that if the psychological impact of cancer was not framed as a normal and understandable response, people would be hesitant to access support when needed.

There is a lack of information about what support is available, at what point it can be accessed, how to access it, and the process of how psychological services provide support. Throughout interviews and discussions people affected by cancer continually referred to uncertainty about where to go when. Some were unaware TTP offered support to people affected by cancer, another had attended MCPS and been told it was too soon to be seen. They felt that being assessed for, or coming along to psychological therapy, was an unknown entity and they didn’t know what to expect. It was clear from conversations that there was not enough explanation by services as to what they did, when they did it, and what was involved.

“I would have liked more support about how things are likely to change down the road and what you can access down the road if you need to. I didn’t go back to Macmillan because

again, I was told right at the beginning it was too early to access something. So, it kind of puts you off. So, I suppose it's maybe making it clear if, if it is too early now, but now is when you need the support, what can you have now and what can you have later?"

Waiting times to start psychological support are very difficult.

Waiting times were referenced across both MCPS and TTP services, as something that people found difficult. There was a recognition that once people had taken the step to access a service, that having to wait for any offer of therapy to begin was challenging.

*"From the time when you are being referred until you actually speak to someone, your mind is going crazy and you don't have anyone really to talk to about **those** problems, like cancer problems, because you don't want to bother people again and again and again. Your friends, your family, yes, they would listen, yes, they would understand. But it's not easy. So, that time before I actually could speak to my therapist, it was awful."*

The importance of being able to talk about cancer in context.

"It feels as though sometimes you have to fit into a box. We can help you with this or we can help you with that. And the thing with cancer is that people with cancer, they're just living life and life still goes on. You know you still have bereavements; you still have to go to work; you still have children to deal with. And my whole experience of all of it has been, we can deal with this, or we can deal with that. And I find that very difficult."

People affected by cancer reflected how a cancer diagnosis impacted vast swathes of their life and shared that they valued having a space to talk about this. They discussed how psychological therapy services generally, often required them to focus on a specific problem for a limited number of sessions. People didn't always feel this could meet their needs in relation to cancer.

Key themes from people affected by cancer – The pathway ahead

When people affected by cancer discussed the development of a pathway between service, the following themes were identified:

Needing psychological support which "gets" (understands) cancer.

"When I looked on their website, it doesn't actually say anything about cancer specifically. As a cancer patient, if it doesn't say anything about cancer on their website, I'm like, "OK, well, they don't have somebody there who knows about that particular experience."

In discussions, people shared how important it was that staff weren't scared of talking or asking about cancer. They felt that if this were the case, it mirrored many other spaces where people were too scared to ask. Whereas participants felt Macmillan had a strong association with cancer, some were unsure whether TTP staff understood cancer. Knowledge that TTP were equipped to deal with discussions about cancer was seen as important moving forward.

People affected by cancer also felt that having a flexible choice of how support was delivered, either face to face, by video call, telephone, or on-line self-help was vital.

"I think the idea of a service that can be accessed online in the community for me would be something I would have found very useful, particularly if the service up here at the QA had not been possible at that time."

Preferences in terms of delivery method of psychological support varied across the group. People felt that this range of preferences should be accommodated in any pathway and that services should be transparent about what range they are able to offer.

[Support being offered away from the hospital/ clinical environment may be desirable.](#)

"And I know logistically, I know this is all very complicated, but I think there should be like a place where you go, and you feel you're supported. Even if you don't get the right support straight away, but you know there are people around there if you need to. I think that's a more kind of holistic approach of the whole thing."

Several people affected by cancer spoke about the hospital being a difficult place to return to, they shared in an ideal version of care how there would be a separate space/building. For others, they valued the proximity of the Macmillan Centre to the treatment setting so that people could just "pop in". However, even for those who valued the Macmillan Centre being in the hospital, the importance of it not feeling like a clinical environment was emphasised. When people spoke of psychological support, they also emphasised that this did not always mean being referred for psychological therapy. People who had accessed the Macmillan Centre valued the volunteers who offered psychosocial support, linking them into other workshops taking place at the centre or signposting to support groups. They talked of the environment as a supportive one, where they could spend time in a safe, calming environment around treatments. Most people felt this was helpful and that having one central location for this was important.

The importance of support after physical treatment for cancer has ended.

“It's got to be ongoing when people need it, in a way that they can access it.”

Many people reflected on feeling isolated and uncertain once (and if) their physical treatment at the hospital ended. However, nearly all participants spoke of the ongoing psychological challenges that cancer presents. As a result of that many people shared their hopes that psychological needs could be cared for in an ongoing way, either with drop ins or follow ups.

The “golden thread” through treatment and beyond.

“There needs to be something that is a kind of a golden thread that's from the beginning, right the way through, until like eventually, you know, hopefully life sort of expands around it a bit at the end.”

People spoke of a psychological support pathway, being integrated and woven throughout their cancer journey. This thread began with initial conversations about how cancer could impact their emotional wellbeing as well as the physical, continued with regular check ins about their emotions at each appointment, and connected into other forms of psychological support from support groups to psychological therapy. They didn't want the thread to be cut at the end of treatment, instead hoping it would link into ongoing support in the community. For this reason, they highlighted the importance of psychological services working in a joined-up way, communicating with and facilitating referrals between each other in a way which is supportive for patients.

Key staff themes – Current provision

Staff across both services told us this about their experiences of working within services who supported people affected by cancer. Whilst some themes spanned both services, some were unique to one service. The key themes were:

Talking Therapies staff expressed low levels of confidence about working effectively with people affected by cancer.

“I have a fear of not understanding the diagnosis, the treatment, and the impact of that. I don't know what the treatment path is for these patients, so I wouldn't be able to fill in the gaps in their knowledge.”

Talking Therapies staff expressed a range of concerns about working with this client group, which included lacking knowledge of cancer and treatments, working with what is considered an emotive and “scary” diagnosis, clumsy or unhelpful use of language in

respect of the diagnosis, and the work bringing up personal difficulties/feelings due to their own experiences.

“It can cause distress and be triggering, as I lost two best friends to cancer. But I guess it can be a bit of a double edge sword, because if you have that personal experience of seeing a loved one go through cancer, you perhaps have more of a shared understanding with your patient.”

MCPS staff concerned about their limited resources and flexibility to meet the needs of people affected by cancer.

“It's really difficult because we have a lot of people that are seeking emotional support and there's only so many [counsellors/ psychologists]. It's hard if they've got to wait a long time.”

Staff within the immediate MCPS team, were concerned about the lengthy waits people experienced to see a counsellor or psychologist. This was also raised by CNS colleagues who referred into the service. They shared their awareness of the limited capacity the service had and their hesitance to refer. Staff were also aware that due to waiting lists, they didn't feel able to respond flexibly to meet people's needs.

The referral process into MCPS is unhelpful to the referrer.

“I think then it became quite frustrating just how much information was needed, because yes, the form was designed to help you triage. But I think we were like, we're not familiar with these things that you're using as a measure to triage. And I think at first, they felt really quite alien to us.”

Both staff who made referrals to, and staff who received referrals as part of the MCPS, raised issues with the referral form. Members of staff from the wider clinical team raised how it was cumbersome to fill in, and shared they felt uncertain as to what MCPS staff wanted within the referral. Staff within MCPS were aware that the wider clinical team found the referral form irritating and were concerned this may put people off referring those who needed support.

Staff across both services have limited awareness of the other.

“I knew of Macmillan, but only heard about the counselling and psychology through your emails about this project.” – TTP staff member

Staff in both services had limited knowledge of the other's service provision. TTP staff had no idea that MCPS existed and were not aware whether they could make a referral. MCPS staff (both in the immediate and wider team) although knowing of TTP, lacked an awareness

of what TTP provided. This resulted in MCPS staff feeling unable to signpost or make referrals for patients to TTP. It became clear that in the absence of detailed information, people's knowledge about services mainly came from third hand information which led to these stories becoming overgeneralised.

“If I've seen the place, I've seen the people and have a bit more understanding, so when I'm working with people, then I would automatically think, oh, this would fit in really well, because I'd have a better understanding. But I don't know anything about them.” – MCPS staff member

Key staff themes –The pathway ahead

When staff considered the development of a pathway between MCPS and TTP, the following themes were identified:

Staff from both services wanted closer working links and improved communication.

“I think it would be really good to have discussion between the services about referrals, to place patients in the right service for them. Maybe at an MDT, like we have with PPPT.”

There was an appetite across both staff groups, for a closer working relationship with the other service. People spoke of wanting to have spaces to discuss referrals, to gather information about cancer, and to learn more about the other service. There was a willingness amongst staff in interviews and discussions for this to be established, and all could see the benefit of a more established pathway.

“It might be helpful if you could have a liaison with them. If they have someone that we sent through, and say we'd onwards referred somebody, and we can say your point of contact would be one of us...you could explain about chemo or radiotherapy to them.”

Better understanding of who does what when.

“So, it would be nice to have a map or some kind of talk to say look, this is available, and this is for these people, and this is the criteria that they need to meet.”

Echoing the experiences of people affected by cancer, staff felt they wanted a clearer understanding of the similarities and differences between services. They also wanted clear guidance as to which service may be best placed to offer psychological support, when and to whom suggesting that some form of referral criteria would be an important part of the pathway.

Findings from Phase 3: Improving the experience

Joint patient staff event

Following thematic analysis and video creation, a joint patient and staff event was held. It was at this joint event where the catalyst film was shared for the first time. There was a low staff turnout at the event, and people affected by cancer fed back that this only further replicated some of the themes discussed (the challenge that this presented will be explored at a later point).

Despite the low staff numbers, the project team fed back the themes from the staff interviews to provide people with a sense of the staff perspective. The people in attendance at the joint event, reflected on the parallels between themes across both sets of interviews and considered these in their decisions on the key priorities moving forwards. Following this discussion, key priorities were decided for the co-design groups. These are outlined below in Figure 7.

Co-design groups – Piecing together the puzzle

The co-design groups met together for a period of 6 hours over a 6-week period, with each group assigned one of the key priorities. Due to project delays, there was a much shorter time frame for the co-design groups to work together than was initially hoped for. Project leads acknowledged this with groups from the outset, noting that the outcomes of the group were likely to be ongoing actions to be worked towards, rather than actionable achievements within the time frame of the group meetings. Each co-design group was encouraged to think of short, medium, long-term goals, setting a direction of travel. An excerpt of these goals can be seen in Figure 7 (full copies can be found in Appendix D). The project team and participants came to see the co-design phase as piecing together a puzzle, acknowledging the interconnected nature between the themes, each being one piece of the much larger puzzle of creating a pathway.

Demystifying and developing awareness of psychological support

The main recommendation from the Demystifying co-design group was the creation of a cancer hub website. Co-design group members agreed it was important to have a place-based website covering the hospital catchment of Portsmouth and South-East Hampshire, where all key services involved in cancer care could unite to share information about what

they provided, when they might provide it and what people could expect. Group members felt this page should be interactive and welcoming, with videos of clinicians and patients, and a frequently asked questions page, providing an idea of what someone might expect if they came along to each service. This differed from existing websites such as the Cancer Map, which people shared they found an overwhelming and unengaging list of possibilities when navigating cancer. Group members were clear that this website should not be limited to information about psychological therapy but also include information about things like local support groups, to be regularly updated. It was felt that this not only acted as a hub for patients, but also for staff to learn more about other services involved in cancer care. The videos would provide staff with an understanding of what services did, so that they could feel more confident having signposting conversations and facilitating a “warm handover” to another service.

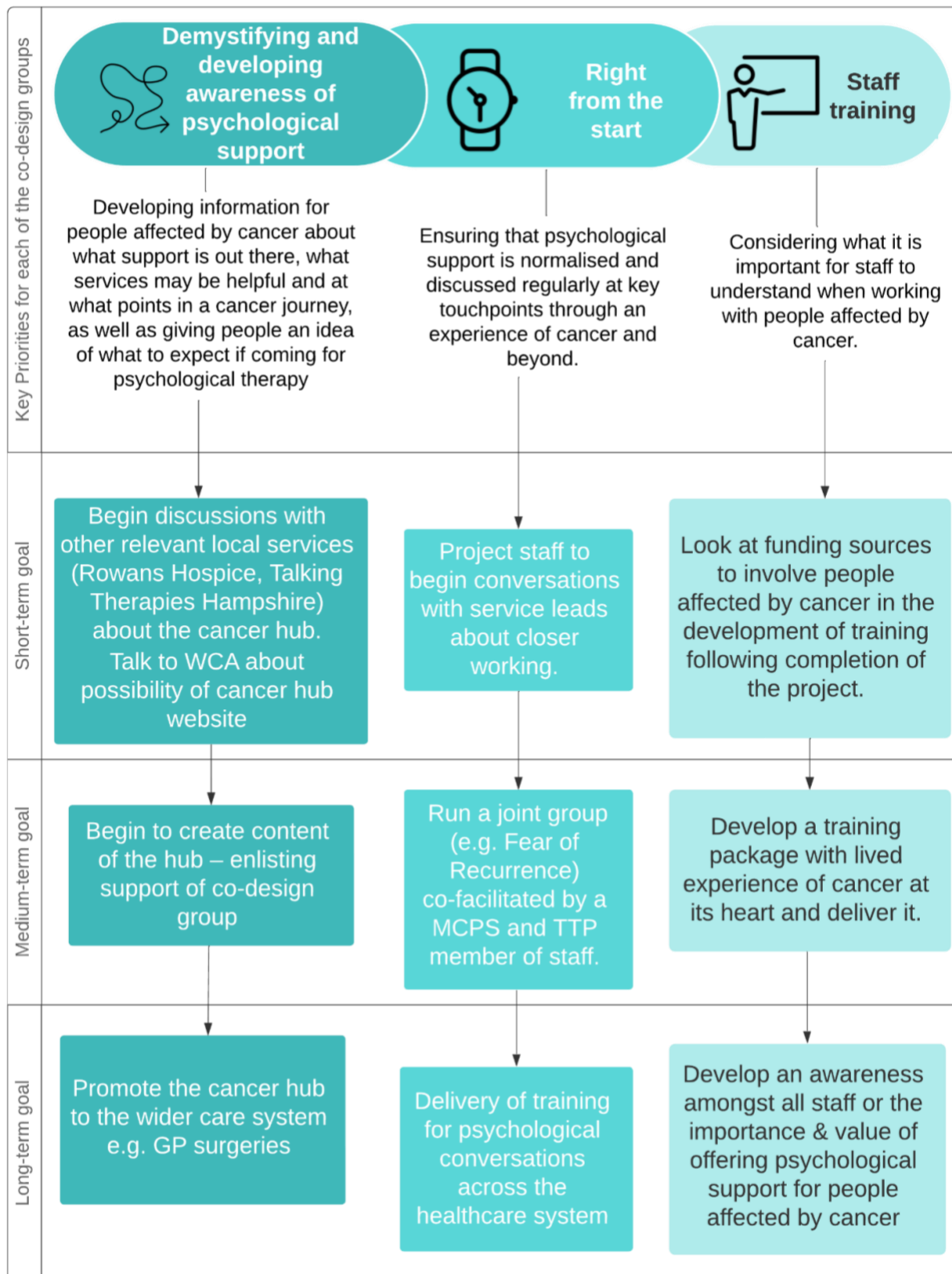


Figure 7: Key priorities and Excerpts of goals from the three co-design groups

Right from the start

There was recognition from the start, that this theme's focus on the involvement of the wider healthcare system presented a challenge for the group. With that in mind, co-design

group members tried to hold in mind a longer-term goal of influencing conversations across the healthcare system, whilst also considering smaller steps psychological services had immediate control over. Group members identified that one of the key moments for getting these conversations right, was when acute cancer care at the hospital ended and patients were discharged back to the care of their GP. This was identified as a point where psychological services could lead by example, in terms of ensuring that conversations were had, and a warm handover was facilitated between MCPS and TTP. The group felt that closer working links between services in doing things such as co-facilitating a group or having a TTP clinic within the Macmillan Centre could begin the improvement of conversations at this touchpoint. Group members felt that doing so was one step towards the golden thread of psychological support throughout the cancer journey.

Staff training

The main recommendation of the staff training co-design group was to build a training package with the lived experience of people affected by cancer at its heart. The discussions between patient and staff group members in this co-design group, highlighted how whilst staff often worried about knowing the “medical side” of cancer, patients felt that their experience was overly medicalised. Patients shared that this was not necessarily the information they’d want their psychological therapists to develop knowledge in. TTP staff in particular felt that training should include a space to ask questions about cancer, to reflect on the experience of cancer and to discuss language. Staff felt that the lived experience of cancer was often missing from training they received. The co-design group decided that the development of a training package for Talking Therapies staff, based on the input of psycho-oncology, cancer healthcare professionals and the lived experience of people affected by cancer, would be beneficial. TTP staff also discussed the importance of having a regular reflective supervision space, to specifically discuss their work with people affected by cancer.

Project evaluation

Successes

Figure 8 highlights some of the successes of the project so far. One of the undoubted successes of the project has been the improved communication between Talking Therapies and Psycho-oncology services in Portsmouth. Prior to the project commencing, there were no established channels of communication and some staff in both services had very little, or sometimes no knowledge at all of the other. As a result of the close working on the project, staff have a greater awareness of each other's service and have a point of contact in each respective service to ask for more information. There have been numerous "ripple" effects of this, one of these being an increased number of handover discussions about referrals between services. The respective project leads now have a point of contact in the other service to ask questions of, whilst also acting as this contact for others within their own service.

Whilst the initial project aimed to create a pathway between MCPS and TTP, communication has also improved with other key local partners as a result of the project. Following the suggested goals of the demystifying group, regular meetings have been established with key services in Portsmouth and South-East Hants, Rowans Hospice Psychology team and Talking Therapies Hampshire. Co-design group members recognised the need for involving all local teams in the solutions identified, to demystify all relevant local services for people affected by cancer. This has already resulted in a number of "warm handovers" with these other local partners.

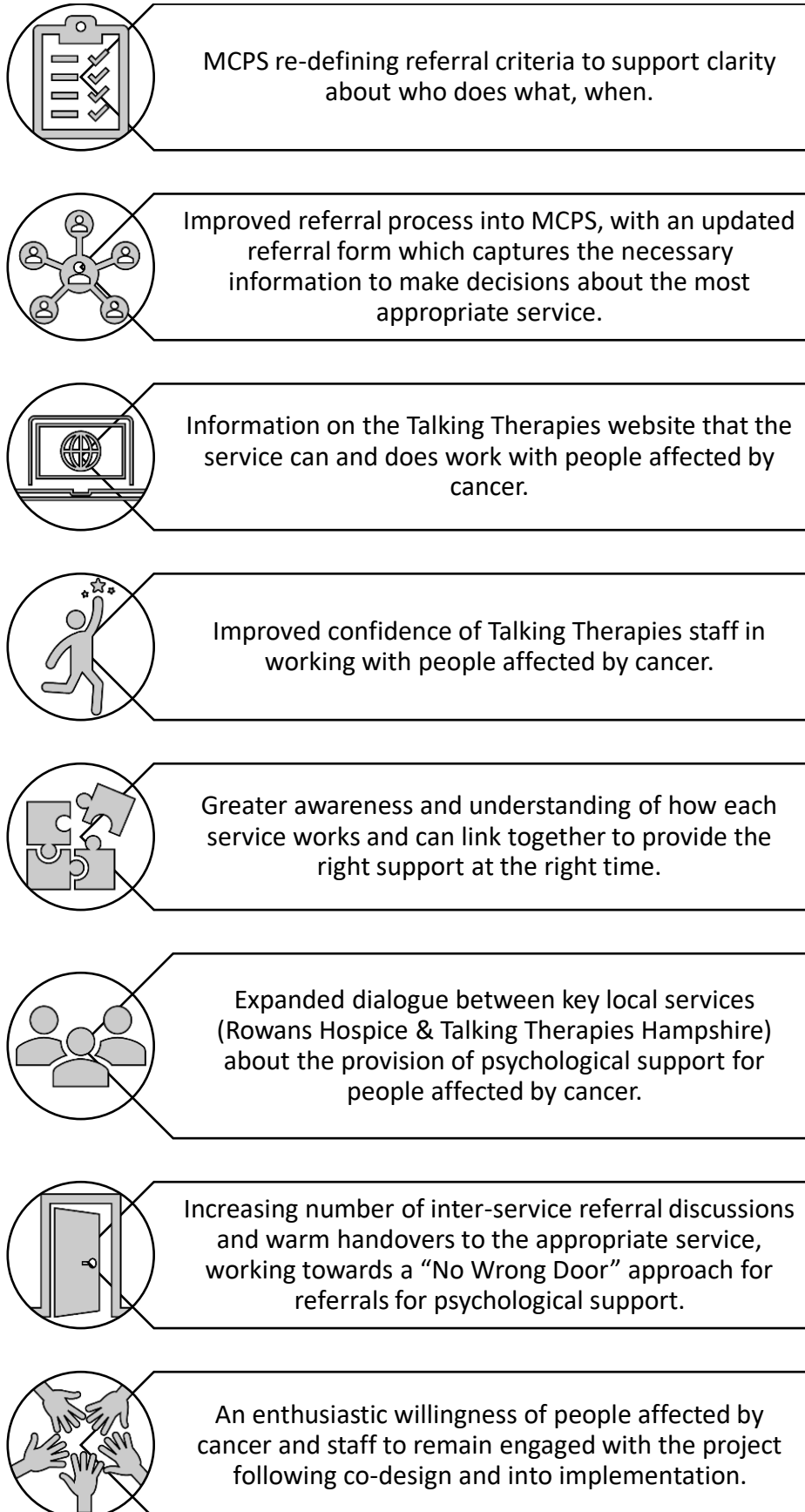


Figure 8. Successes so far

When selecting EBCD as a method, the project team could not have foreseen how impactful this would be for participants. For the project team, whilst there were inevitable challenges, the methodology lent itself well to bringing two services together to think about the puzzle of the pathway. For two services who had little contact prior to starting the project, the necessity of working the approach out together facilitated a working partnership. For the TTP staff involved in particularly the co-design phase, the impact of spending just a few hours in those groups was significant. Staff reported feeling more confident following co-design groups to work with this client group, with one staff member feeding back, “*This collaborative mixture of patients and staff working as equal partners now feels vital for designing anything.*” People affected by cancer who participated in the interviews, fed back how important it was to share their story and for it to be heard. There was a sense of pride around their involvement which is encapsulated in the following quote:

“If you want to be heard, if you want to do something to make improvements, get involved. You’ll be surprised how good it feels, being part of something that touches you intimately, but also so many others directly.”

Challenges and lessons learned

Project breadth

One of the unique challenges of the project was its breadth, asking people about a broad range of experiences, spanning two different services across two different Trusts. Many of the examples of EBCD found, prior to the project commencing, involved one service, either creating a pathway within the service, or trouble shooting an existing one. The use of EBCD within the project, really brought to life the experiences of people affected by cancer and staff across services. However, taking this approach across services brought a range of challenges from ensuring data sharing agreements were in place, to the location of co-design meetings, to differing Trust policies on patient and public involvement.

Delays to the project

The initial project funding supported the Senior Clinical Psychologist’s time for a period of 12 months. However, due to the unforeseen delays outlined below, there was a risk that this contract might expire. To alleviate these challenges, further funding was sought from WCA to fund the psychologist’s 0.6 WTE post for an additional three and a half months. This

allowed the project team to begin recruitment in September 2023, knowing they had seven months to complete the project.

Time taken to establish a partnership across services

Establishing a partnership between the two services was vital to the success of the project, rather than one planning and “doing to” the other. Time was taken to build this relationship over the early months of the project. This laid the foundations for a successful project but undoubtedly impacted early project pace.

Staff attendance at events

One of the most disappointing parts of the process for the project team, was the low staff attendance at the joint patient staff event. People affected by cancer shared their sense that this reflected many of the themes that they had discussed in their interviews, and understandably felt let down. Whilst this low staff turnout in itself acted as a catalyst for further staff involvement in the co-design groups, it is an important lesson for future EBCD projects. Other things to consider in the future may be the hosting of such an event in a hybrid format (both online and in person), the planning of the joint patient staff event further in advance and reiterating to staff the importance and value of their attendance.

Information governance

One of the key delays to the project, was a result of uncertainty as to whether data sharing agreements were in place across Trusts, and how data could be shared in a secure way. The sharing of interviews was critical to the success of the project, to enable analysis and the creation of the patient video. This information was needed prior to recruitment, to enable transparency for participants as to how their experiences would be used and stored safely and securely. Delays in information governance sign off meant that the project team were unable to start recruiting participants until nine months into the initial funding period. Whilst an acceptable method was eventually agreed this meant initial momentum in the project was lost. Future EBCD projects, particularly those that span organisational boundaries, should ensure that information governance principles are considered from the outset.

Costing of EBCD

Central to the ethos of EBCD is reimbursing patients involved for their time, in recognition of their contribution to the design of service improvements. However, within the initial project proposal there had been no costings for such payments. There was variation across the two Trusts involved in the project, in terms of their policies for public and patient involvement

payments. This presented a dilemma for the project team, who strongly believed that people affected by cancer should be paid for their involvement, with only one service having funding to do this. In this case a solution was found by applying for a Macmillan support grant. However, the process of searching for funds and applying for the grant took up valuable time during a labour-intensive period of the project. Future projects should factor in the payment of patient expenses **and** reimbursement of their time devoted to the project. To support the ongoing involvement of people with lived experience in designing and developing services, Integrated Care Boards (ICBs) should ensure that there is a consistent approach to involvement payments across NHS trusts. On a local level were the project team to use EBCD again, involvement payments would be advertised from the outset of the project in recruitment letters, posters, and information sheets. Being transparent about the time commitment, and the opportunity for payment from the outset is vital to enable a diverse group of people to participate. ICBs should work with Trusts to standardise involvement payments across the local area, to prevent the further exacerbation of health inequalities through service design and development.

Timeframe for EBCD

Due to delays within the project, there was a limited period of time (6 weeks) in which co-design groups could take place. The EBCD toolkit (Point of care foundation, n.d., c) gives an example of EBCD groups “meeting fortnightly moving to monthly for about 6 months”, to ensure that there is time between meetings for plans to be actioned and outcomes to be achieved. Within the limited time available for groups, the project team were unable to fully capitalise on people’s interest in the project. Whilst plans for the future were made, having a longer period of time would have enabled richer discussions, and allowed participants to begin implementing changes alongside the groups. EBCD has been successfully adapted to create accelerated forms of the method (Locock et al, 2014) and this may be something to consider in future projects.

A challenge to and for services to consider

Something regularly discussed but not thoroughly explored in co-design was the way in which psychological therapy services are delivered. People affected by cancer shared through interviews how blocks of time-limited therapy to address specific problems did not meet their needs. They spoke of wanting ongoing psychological support as and when necessary, not necessarily through a formal psychological therapy but having somewhere

they could return to where the life changing experiencing of cancer was understood. Many preferred the idea of this place being away from the hospital site, in the community. Some may argue that this need could be addressed by some of the aims of the pathway, i.e. ensuring people are aware of psychological therapy available from Talking Therapies Services after hospital care has finished. However, the hopes of people affected by cancer heard in the project, indicated a desire for a fundamental shift away from the way in which services are currently commissioned and delivered. It indicates a need for psychological therapies services to actively work alongside communities, to recognise and value their expertise, and work with them to design services, where they desire them to be. Whilst this remit may have been beyond the scope of this particular project, as the NHS increasingly emphasises the need to co-design services with the communities they serve (NHS England, n.d., b), commissioners and NHS trusts need to be ready to adapt.

Actions still to take

When the aims of the initial project shifted, there was a recognition that it would be unlikely result in a completed pathway by the end of the project. The process of EBCD has not necessarily given MCPS or TTP staff a written template of how the pathway should look. The pathway processes still need to be established. As previously outlined each co-design group also set medium- and long-term goals to guide the work following on from the project. Plans the project team have made to support the ongoing progress towards these are:

- Senior Clinical Psychologist assigned 1 day a week in job plan to continue the work of the project.
- Ongoing regular meetings between project leads.
- Regular meetings with key local partners to establish pathway.
- Continued involvement of people affected by cancer, who are enthusiastic and willing to continue working towards recommended goals. There is grant funding outstanding to support payment of their time.

At this stage in the development of the pathway, it is difficult to provide a clear description of how it will look, and therefore how it will continually be reviewed. As discussions continue between multiple stakeholders, a key concept for the project team to hold in mind

will be “How will we know this is working for people affected by cancer? How will we know this is working for staff?”

Sharing and dissemination of findings

From the co-design phase of the project, the need to share the findings with other local services became evident. The project team have started this work, initially sharing the findings with the neighbouring Talking Therapies service (Talking Therapies Hampshire) and Rowans Hospice Psychology team. These partners were also invited to the project celebration day where we shared findings of the work and celebrated the involvement of all participants, alongside patient and public involvement representatives, Trust executives, participation leads, and staff from WCA. The findings have also been shared with psycho-oncology staff members working to build similar pathways across the country, as a means of sharing learning and informing work nationally. Findings from staff interviews about cancer training needs have been fed into the work of a national Talking Therapies working group, which is updating and redeveloping the Long-Term Conditions training for staff across the UK.

It is apparent from the project’s findings and direction, that the findings of the work are not only relevant for Talking Therapies and Psycho-oncology services. With this in mind the project team have actively sought to share the findings with professionals outside of the core psychological professions. The project was submitted to a national conference for cancer professionals, and the findings have been shared at a Wessex wide event for Allied Healthcare professionals and the registered cancer workforce. The project team are keen to continue sharing the findings with varied audiences locally, regionally and nationally.

Conclusion

The project set out to understand the experiences of people affected by cancer and staff working with them across the two services. The use of EBCD, gave the project team a wealth of rich information about people’s experiences and highlighted the key problems with psychological support in its current form. Some of these were specifically related to one or both services, but also spanned the entirety of peoples’ experiences of cancer, involving teams ranging from oncology to GP services. Understanding these experiences, is not necessarily impactful without action to improve them and the co-design groups worked hard to begin this huge task. The conversations started within these groups, have continued

after the completion of the project between the two services directly involved, with local partners, with colleagues across the region and the country. The project team will continue to work towards the vision set out in the project, to create an effective cancer psychosocial support pathway for people affected by cancer in and around Portsmouth.

Recommendations

- The development of an online place-based Cancer Psychological Support information hub, to contain information about services available, how those services work, referrals processes, how therapy works and in what environments therapy will be offered. This information should include illustrative videos of the services, along with videos of people who have been affected by cancer talking about their experiences of therapy. There will be additional information for carers and professionals.
- The continued development of closer working links between the Macmillan Counselling and Psychology Service and Talking Therapies Portsmouth, including working towards co-facilitating interventions such as therapeutic groups and co-locating individual therapy within the Macmillan Centre.
- The development of a training package for Talking Therapies staff to build their confidence in working with people affected by cancer. This training package should bring together the expertise of psycho-oncology services, cancer healthcare professionals and people affected by cancer.
- Psychological services should promote the role of conversations about the psychological impact of cancer across the cancer pathway. People affected by cancer clearly articulated that psychological support is not solely the role of specific psycho-oncology and Talking Therapies teams. Psychological services should consider how they may upskill the wider healthcare workforce, to normalise, recognise and understand the psychological impact of cancer from diagnosis, through treatment, and beyond.
- When building pathways between specialist psycho-oncology services and Talking Therapies services, time should be taken to build a partnership with each team recognising the other's expertise, remit, and limitations. This enables staff to learn about other services and builds confidence and trust in onwards referrals. All of this supports the goal of "no wrong door" to services, where someone can present at one service, and

whereby staff with an understanding of the wider cancer system can complete a “warm handover” to the most appropriate service for that person at that time.

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Appendices

Appendix A Patient interview schedule



The story of your journey

Introduction

1 Your journey with psychological support so far

(Referral – assessment - treatment – discharge – follow-up)

1.1 The first time you felt you may need some psychological support

- What were your first thoughts about accessing psychological support? What made you think you needed to do so? How did you feel about doing so? **Was your experience of cancer part of the reason you felt you needed support?**

1.2 The first time you discussed accessing psychological support with a healthcare professional (e.g. your GP, your clinical nurse specialist)

- What happened and what stands out in your mind about that?

1.3 Any later meetings with other healthcare professionals where you discussed psychological support

- What happened and what stands out in your mind about that?

1.4 The referral process

- What was it like completing the referral either yourself or with someone else? How long did it take? Did you have all the information you needed? Were you updated about the outcome? How were you updated? **Did you feel your experience of cancer was captured in the referral?**

1.5 Your initial assessment

- How long was the wait before your assessment? What was it like during the gap? (eg, worrying time? Anxious?)
- What were your first impressions of the hospital environment or the centre (the clinic reception desk, waiting area, the general place, other people there, staff)? **If your initial assessment was online what was this like? Did you have contact with any staff prior to the appointment?**

1.6 The initial assessment with your psychological therapist

- What are your memories of that first visit?

- What was it like to make your next appointment? Did you have to wait to do so? Did you leave with a clear idea of the plan?
- Were you asked about your experience of cancer? What are your memories of this?

1.7 Back to family and friends

- What role did your family, and friends play in you accessing psychological support? What was their response? (e.g., problematic? Supportive?)

1.8 Starting psychological therapy

- Tell me about the time your experience of psychological therapy?
- How long did you have psychological therapy for? Did you feel ready for therapy to finish?
- Did you have therapy face to face or online? Did you do a mixture? What was it like doing it this way?
- Did you talk about/feel able to talk about your experience of cancer?

1.9 After psychological therapy ended

- Tell me about the follow-up after treatment.
- How much information did other healthcare professionals (e.g. your GP) have about the therapy you had? Were they well-informed?
- Did you know/were you told about how and where to access additional psychological support when treatment ended? Were you offered any information on support in relation to cancer?

2 Issues

2.1 Overall satisfaction

- Broadly speaking, how satisfied have you been so far with the psychological care and treatment you have received?
- What are the best bits and worst bits of the Macmillan Counselling & Psychology service? What are the best and worst bits about Talking Change? If cancer was talked about in your therapy what were the best and worst bits about talking about that with your therapist?

2.2 The information you received

- Did you find it difficult or awkward to communicate with staff from the service?
- What would you have liked more information about?
- Have there been times when you have been given conflicting or contradictory information?
- Did you feel progress was discussed regularly?

2.3 How much influence you had

- Have you had any choice in your psychological support and the type of therapy you were offered?
- Are there any things in which you would like to have had more 'say'?

2.4 Your relationships with the staff you met

- Tell me about your relationships with staff.

- Do you feel as though staff have accompanied you on this journey, or do you feel you have done it very much on your own?

2.5 What other types of support did you have?

2.6 How did you manage to cope?

3 Best and worst bits

3.1 Where would you say are the crucial points in the journey – moments of truth?

3.2 Are there crucial touch points? The parts we should focus on in the design process?

3.3 What were the best and worst parts of your whole experience?

3.4 Awareness of both services

- Before this project were you aware of/had you heard of either Talking Change Talking Therapies or the Macmillan Counselling & Psychology service?

- Did you know they both support people affected by cancer?

- How do you think we could work better together?

3.4 What would you do to improve psychological support

- Based on your first-hand experience, if you were looking to redesign and improve the psychological support for people affected by cancer where would you begin? Imagine we were setting it all up from scratch. (This question includes physical environment, the process itself, staff attitudes and behaviour, etc)?

Appendix B Interview schedule for staff interviews (MCPS)



1 Introduction

- Tell me a bit about your role within the Macmillan Counselling & Psychology Service (MCPS)?

2 Staff experiences of MCPS

- Can you tell me what is it like working in in MCPS?
- What's good about working here?
- Can you give me an example of a positive experience you have had?
- What's not so good about working here?
- Can you give me an example of a negative experience?
- Can you describe a typical day's work in this service?
- What do you think are the main problems with this service from the point of view of staff?
- How does working in this service compare to other places you have worked or are working?

3. Perceptions of patient experience

- What do you think it is like being a patient in this service?
- What are your perceptions of the service you are providing to patients?
- Which patient needs are met? Not met?
- What do you think are the major problems faced by patients?
- What could be improved for patients in this service?
- Do you notice differences in the experiences of patients coming from different teams/specialities?
- In your opinion, what are the major 'touch points' or critical moments in the patient journey (the things or events that really shaped their overall experience)?
- Overall, do you think that you provide the care you would like for yourself and your family?
- Would you be happy if a member of your family was going to be treated here? What would be the things you'd feel the need to tell them about?
- What aspects of the service would you be happy or unhappy with?

4. Awareness of both services

- When did you first become aware of/learn about Talking Change Talking Therapies?
- Did you know they offer support people affected by cancer? Has anyone you've worked with accessed Talking Change (or an equivalent service e.g. iTalk)? What's your perception of their experience of that?
- How do you think Psychological services at the hospital (e.g. MCPS) could work better with psychological services in the community (e.g. Talking Change)?

5. Improving the service

- What do you see are the main priorities for improving the service from the staff point of view?
- How should things develop?
- What other things do you feel would help to improve your experience and the experience of other staff in this service?
- What do you think patients would identify as things that would help to improve patient experiences?
- Based on your first-hand experience, if you were looking to redesign and improve the psychological support for people affected by cancer where would you begin? Imagine we were setting it all up from scratch. (This question includes physical environment, the process itself, staff attitudes and behaviour, etc)

Appendix C Interview schedule for staff interviews (TCTT)



1 Introduction

- Tell me a bit about your role within Talking Change Talking Therapies (TCTT)?

2 Staff experiences of TCTT

- Can you tell me what is it like working in in TCTT?
- What's good about working here?
- What's not so good about working here?
 - Have you worked with anyone affected by cancer (person receiving the diagnosis/a carer/family member/friend of someone who received a diagnosis) whilst at TCTT?
- Can you tell me about what the experience of doing so was like? What were the high and low points?
- If you haven't worked with someone affected by cancer, would you have any concerns about doing so? What might they be? Would you have any hopes for this work?
- What do you think are the main problems in working with people affected by cancer from the point of view of staff?
- How does working in this service compare to other places you have worked or are working where people have been affected by cancer?

3. Perceptions of patient experience

- What do you think it is for a person affected by cancer in TCTT?
- What are your perceptions of the service you are providing to patients affected by cancer?
- Which of their needs are met? Not met?
- What do you think are the major problems faced by patients affected by cancer?
- What could be improved for patients affected by cancer in this service?
- Do you notice differences in the experiences of patients coming from across the different treatment pathways in TCTT? What are the differences you've noticed between those patients have been affected by cancer, or what you imagine they might be?
- In your opinion, what are the major 'touch points' or critical moments within the patient journey (the things or events that really shaped their overall experience) in TCTT? How does/might these touchpoints differ for a person affected by cancer?
- Overall, do you think that you provide the care you would like for yourself and your family?
- Would you be happy if a member of your family was going to be treated here? What would be the things you'd feel the need to tell them about?
- What aspects of the service would you be happy or unhappy with?

4. Awareness of both services

- When did you first become aware of/learn about the Macmillan Counselling & Psychology Service (MCPS)?
- Did you know about the support they offer to people affected by cancer? Has anyone you've worked with accessed MCPS? What's your perception of their experience of that?
- How do you think Psychological services at the hospital (e.g. MCPS) could work better with psychological services in the community (e.g. Talking Change)?

5. Improving the service

- What do you see are the main priorities for improving the service for patients affected by cancer from the staff point of view?
- How should things develop?
- What other things do you feel would help to improve your experience and the experience of other staff in this service?
- What do you think patients affected by cancer would identify as things that would help to improve patient experiences?
- Based on your first-hand experience, if you were looking to redesign and improve the psychological support for people affected by cancer where would you begin? Imagine we were setting it all up from scratch. (This question includes physical environment, the process itself, staff attitudes and behaviour, etc

Appendix D- Co-Design Group Goals

Taking improvement ideas forward – goals from the Demystifying co-design group

Short term goals – Next 4 weeks

- Talk to Talking Therapies Hampshire (TT Hants) about the project.
- Talk to Rowans Hospice about the idea of the cancer hub. Distinguish between in person palliative care hub meeting they currently have.
- Talk to Gemma, Wessex Cancer Alliance Communication lead about the practicalities of the hub: *Can they help us set up a separate website? What might be the cost of doing so? Can they connect us with someone who can help?*
- Based on conversation with Gemma – explore digital transformation funding.
- Macmillan Counselling & Psychology (MCPS) service to rewrite referral criteria.
- For each of the 4 main services involved in the hub (MCPS, Rowans, Talking Change (TC), TT Hants to have a statement in relation to their work with people affected by cancer.
- To think about themes of the videos on the hub. What are most important themes? Who might appear in videos?

Medium term goals – 6 months to a year

- Start to apply for any digital transformation funding required.
- Start to think about and write specific content of the hub – co-design team, other interested staff members and people affected by cancer.
- MCPS & TC to discuss and plan referrals process between services (how to avoid duplication of work etc).
- Staff in both services to have chance to shadow work in either service.
- In conjunction with other co-design theme – to deliver staff training which explains about outcomes of project including the hub.
- Starting point to more co-working – to co-deliver a fear of recurrence group with a member of TC & MCPS staff. (*see details next page)
- To establish way of collecting further data to record and evaluate people affected by cancer accessing each service.
- **Within a year to have a hub!**

Long term goals – 1-3 years

- TC clinics for people affected by cancer to be held in the Macmillan Centre. Possibly offering this to TT Hants too?
- Adding further content to the hub and maintaining it.
- Promoting the hub to the wider care system e.g. GP surgeries, cancer care co-ordinators.

Taking improvement ideas forward – goals from the Support from the start co-design group

Short term goals – Next 4 weeks

- Emily to discuss at level 2 psychological skills training in April (this is a training session we deliver for clinical nurse specialists, allied health professionals working in cancer, cancer support workers based at the hospital). *To ask people what gets in the way of having these conversations? We know this is important to patients from our project, how could we start to make this happen? Who don't you ask and why?*
- Dave and Emily to hold meeting with clinical leads in respective services to continue discussions about closer working.

Medium term goals – 6 months to a year

- To run a co-delivered group (e.g. fear of recurrence) between Talking Change & Macmillan Counselling & Psychology service.
- To be moving towards having a clinician from Talking Change in the Macmillan Centre.
- To have developed training to have psychological conversations and how to manage the emotional impact.
- For training to include links to other co-design themes e.g. cancer hub idea in demystifying group. This could help further normalise the impact.
- To have sought guidance on how we can make such interventions culturally sensitive/inclusive.
- *To identify a hospital team who are perhaps willing to put psychological questions in each appointment to the test? So we can evaluate the impact of having these conversations, how staff find them? Can further shape prompts etc.*

Long term goals – 1-3 years

- Delivery and further roll out of training based on feedback from the trial to other teams across the hospital.
- Based on feedback, developing prompt for IT systems to explore psychological wellbeing.
- Starting share training about regular psychological check ins with wider healthcare workforce e.g. GP surgeries.

Taking improvement ideas forward – goals from the staff training group

Short term goals – Next 4 weeks

- Look at possible sources of funding to involve people affected by cancer on a continued basis

Medium term goals – 6 months to a year

- Monthly drop-in between MCPS and TC on Teams -> need to confirm governance and define the space but with the idea of being a space to ask questions about cancer
- Develop a training package with lived experience at its heart
- Run a training session
- Funding – understand sources

Long term goals – 1-3 years

- Regular supervision
- Trained workforce – ongoing training for level 3 & 4, and in the community
- To have developed an awareness amongst all staff of the importance & value of offering psychological support for people affected by cancer
- Know how many people Talking Therapies Portsmouth work with that are affected by cancer