

Health and Social Care Alliance Scotland (the ALLIANCE)

Cancer prehabilitation focus groups: Insights report



Executive summary

The findings in this report reflect the views expressed by 14 people affected by cancer who attended four focus groups at the end of 2021. The focus groups provided a platform for attendees to share their lived experience of cancer as well as their views on proposed cancer prehabilitation services in Scotland.

The following report breaks down the findings from these focus groups into five key areas:

Awareness and perceptions of
'cancer prehabilitation'

Accessing cancer
prehabilitation support

Perceived cancer
prehabilitation support needs

Role of information and digital
technology

Wider themes for consideration



Mixed **awareness and perceptions of 'cancer prehabilitation'** emerged during our discussions. Those who did have a prior knowledge of the concept of prehabilitation had mostly already been involved in cancer service development through the capacity of either a working or volunteering role. Generally, people thought that the current definitions of cancer prehabilitation were too abstract, complex and clinical. There was unease with some of the terminology used, particularly the word 'prehabilitation' itself, and words such as 'assessment' and 'abilities' which some people said could cause anxiety. As an alternative, people suggested providing more detailed real-life examples of what prehabilitation might involve for them personally. Others suggested that the language used to describe prehabilitation should be more human and motivational.

Whilst most people we spoke with were enthusiastic about the prospect of **accessing cancer prehabilitation support**, this was not quite universal. A view was shared that, to those with a good knowledge of health, nutrition and psychological wellbeing, this information may be seen as 'insulting.'

There were no strong opinions on who should introduce the concept of prehabilitation to people affected by cancer and their families. Some suggested this could be introduced by their consultant or cancer nurse specialist. It was emphasised repeatedly that the offer of prehabilitation should be made verbally, ideally in a face to face setting.

The prehabilitation offer, it was argued, should be an integral part of a continuum of care, with nutritional, physical and psychological support available before, during and after cancer treatment. Speed of access to treatment affected people's perception of whether or not prehabilitation would have been feasible in their circumstance. For some, they could not see how they could have had time to improve their physical or psychological health within the tight timescales between diagnosis and treatment commencing. For others, they would have welcomed any kind of prehabilitation support offered to them, primarily to provide them with a distraction from their own worry and anxiety about what might happen in the future.



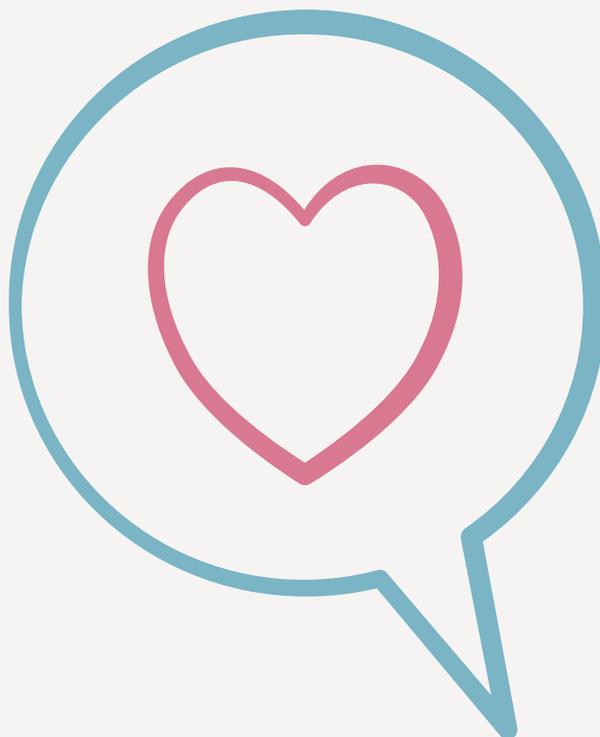
Barriers to accessing prehabilitation services were also discussed, with some people sharing the view that cancer support services are often centralised with less services available locally, particularly in rural areas. However, there was some support for all aspects of the prehabilitation offer (physical, nutritional and psychological support) to be made available in one location. It was agreed that this offer should be person centred and flexible to accommodate people's busy life schedules and individual needs.

When discussing perceived **prehabilitation support needs**, the most recurring theme by far during all discussions was the need for more emotional and psychological support to be made available.

Positive support for potential prehabilitation interventions around physical activity or nutritional needs was mainly forthcoming from people who had experienced their own physical or nutritional issues or challenges. Those who had faced tight timelines prior to their cancer treatment, or who already felt fit, struggled to see the benefit of such support.

The need for services to be better integrated was also a recurring theme. People reported that the current system feels disjointed and compartmentalised with different professionals and different services working in their own silos. It was highlighted that the third sector plays a key role in this regard, filling what was described as the 'gaps' in specialist cancer support.

In terms of other support needs, there was a desire for greater access to peer support and companionship from other people affected by cancer as part of any prehabilitation support offer. People spoke of a desire for out of hours access to support from a professional involved in their care. People also asked for telephone helplines to be staffed in a manner that would allow them to receive advice when it is needed, rather than hours or sometimes days later. A recurring theme was the perceived benefit of having access to a single point of contact throughout their cancer journey who gets to know both them and their families. People felt that such a role should be introduced to them as part of the prehabilitation offer as early as possible following diagnosis.



In terms of the **role of information and digital technology**, people were generally very accepting of the need for, and benefits of, written and other information to help them self manage aspects of their own care. However, there was some feedback around information overload following a cancer diagnosis.

People also spoke about the importance of being able to access their own health information, with feedback on how daunting it can be leaving an important appointment with nothing in your hands for reference or to share with loved ones, such as written information on diagnosis or a care plan. This was exacerbated by COVID-19 restrictions which prevented family members from attending appointments to offer additional support.

Another recurring theme was the need for more support and signposting from professionals to help people identify trusted sources of online information. People generally welcomed digital developments that would improve access and signposting to trusted sources of online cancer information – particularly if the information could be tailored to their own specific cancer and their own individual information needs and circumstances.

There were mixed views on using online tools for clinical and other types of interactions. Some people did see added value in having access to digital tools to support clinical interactions, particularly from those people who had routinely experienced barriers when accessing more traditional face to face services. Others emphasised their desire for face to face support from a professional as they felt it was invaluable and should not be lost. Whilst people generally ranked online communication tools above telephone conversation, again, people said that nothing compared to the personal connection of meeting face to face.



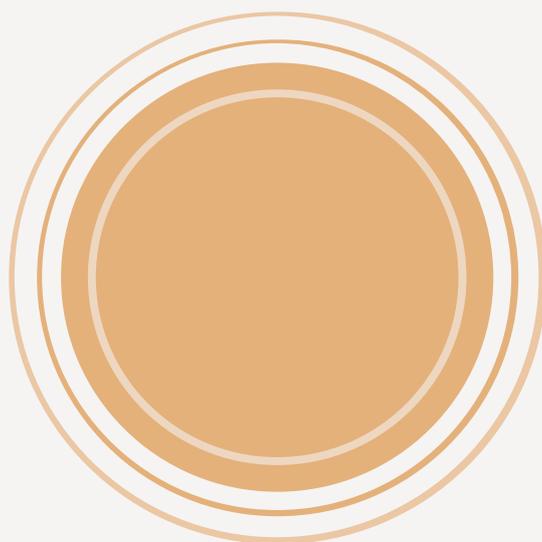
Wider themes for consideration included people's experiences of poor communication and disjointed care, with some criticising the tendency of health professionals to assume unrealistic levels of understanding, often leaving people affected by cancer confused by clinical jargon and terminology.

Those people who went into detail about their caring responsibilities described challenging circumstances when trying to juggle their own appointments as well as their caring responsibilities. This compounded feelings of guilt, as well as a desire not to worry others, with some carers even sharing that they would hide their cancer diagnosis. People spoke of their worry and anxiety over what would happen to the people they care for should they, as carer, be incapacitated or hospitalised for treatment.

People felt strongly that family support should be integral to any prehabilitation service offer. It was also noted that the gap in family support had widened and had been exacerbated by COVID-19 restrictions, with family members unable to attend appointments.

There was concern expressed about the impact of cancer treatment on people's working lives. Being able to maintain employment was important for most people in work, and a concern for some. There was worry about the impact on people's finances if they were unable to continue in employment or if they were to take a lengthy period of sickness absence. Several people also spoke about the struggle of juggling their working life alongside their caring and other responsibilities, whilst also struggling to find time to attend their own healthcare appointments and manage their own health.

Lastly, the COVID-19 pandemic had an impact on the experiences of all the people we spoke to at our four focus groups. People told us that service changes due to COVID-19 had negatively impacted their experience of accessing cancer services. Living and coping with COVID-19 had also compounded already higher levels of anxiety, but again oftentimes with no or limited sources of emotional or other support, with COVID-19 impacting upon the availability of such services.



The experiences and views shared at these focus groups have shaped the recommendations the ALLIANCE will make to the Scottish Government, directly influencing the design and delivery of cancer prehabilitation services in Scotland. Our recommendations include:

1. Continue to engage with people affected by cancer to assure any resultant cancer prehabilitation service proposals meet the needs of current or future cancer prehabilitation service users and their families or supporters. This should include targeted engagement with the under-represented voices identified in section six to identify potentially different perspectives.

2. Ensure people affected by cancer have access to flexible, person centred nutritional, physical and psychological support before, during and after cancer treatment as part of a continuum of care based on individual need.

3. Develop careful messaging through social marketing and other health communication methods to promote the benefits of psychological, physical and nutritional interventions. Messaging and communications must take account of individual preferences for language and terminology; different levels of understanding and health literacy; and potential sensitivities regarding physical or psychological health experienced by people newly diagnosed with cancer.

4. Design cancer support services, including prehabilitation, that reflect the standards and quality of care expected by people affected by cancer, including, but not limited to an expressed desire for:

- **a timeous offer of prehabilitation support immediately following diagnosis;**
- **personalised, local and flexible prehabilitation service provision that includes options for digital service provision and face-to-face services that create opportunity for personal connections;**
- **out of hours access to support from a professional involved in their care throughout prehabilitation and beyond;**
- **telephone helplines or single points of contact to be staffed;**
- **greater ease of access to care plans and results of assessments and/or tests for both the patient and all clinicians involved in their care;**
- **the burden of completing assessments and questionnaires to be kept to a minimum;**
- **improved signposting and access to trusted sources of information online for people affected by any cancer, including rare and less survivable cancers;**
- **greater involvement of family members or supporters in clinical discussions if the person affected by cancer wishes them to be.**

5. Disseminate the findings of this report widely, alongside other available sources of information on people's lived experience of cancer services, to ensure that cancer prehabilitation service design decisions are influenced by what people affected by cancer have told us matters most to them.

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1. Introduction

Scottish Government is leading a programme of work across Scotland to implement actions 24 to 27 of the Cancer Recovery Plan¹ to design and deliver prehabilitation services for people affected by cancer across Scotland.

To deliver on this commitment, Scottish Government is working with a range of service providers including the NHS and third sector partners, to develop proposals for cancer prehabilitation services that aim to help people cope with the impact of a cancer diagnosis; and minimise the potential negative effects of any treatments that lie ahead.

Cancer prehabilitation services will help make sure people newly diagnosed with cancer are as physically and emotionally prepared as possible for their cancer treatment.

Potential developments could include new national digital resources and tools; implementing screening practices; and advising on pathways which will support access to universal, targeted and specialist nutritional, physical activity and psychological wellbeing support and services.

2. Background and context

Whilst there has been a lot written about how cancer prehabilitation should support people, there is also a lot that is still unknown. As such, Scottish Government's Cancer Prehabilitation Implementation Steering Group (CPISG) sought engagement support from the Health and Social Care Alliance Scotland (the ALLIANCE) and its Macmillan Lived Experience Programme, funded through the national Transforming Cancer Care Programme.

Transforming Cancer Care (TCC) is a partnership between Macmillan Cancer Support Scotland and the Scottish Government. The main aim of the Transforming Cancer Care Programme is to ensure that everyone diagnosed with cancer has a dedicated support worker offering guaranteed emotional, practical and financial advice from their cancer diagnosis onwards. The Programme also aims to join up support across hospital, GP and community settings to ensure people's needs are assessed at the point of their cancer diagnosis, and make sure people have opportunity to access services tailored to their individual needs. The ALLIANCE has been commissioned to assure the lived experience of people affected by cancer is central to the TCC programme.

CPISG were keen to hear from and explore the views, insights and understanding of prehabilitation from people who have had direct experience of cancer - personally, or as a supporter or carer of someone who has had a cancer diagnosis.

In response, the ALLIANCE co-ordinated the promotion and delivery of focus groups in November and December 2021, engaging directly with 14 people affected by cancer.

1. <https://www.gov.scot/publications/recovery-redesign-action-plan-cancer-services/>

3. Method

3.1 Promotion

In total, eight focus groups dates were promoted offering a mix of morning, afternoon and evening sessions, as well as a mix of either online participation via Zoom or face-to-face sessions to be held at the Maggie's Centre in Glasgow. Dates were promoted widely across the ALLIANCE membership networks, social media, the ALLIANCE website, and across Scottish Government Cancer Policy Unit networks. These included Cancer Prehabilitation Implementation Steering Group members and associated sub-groups; Transforming Cancer Care Programme Partners; Scottish Cancer Coalition; and Less Survivable Cancers Taskforce.

No-one signed up for the first two online sessions in early November, most likely due to short timescales between initial promotion and the first two dates. Also, the two planned face-to-face sessions at the Maggie's Centre in Glasgow in early December did not attract enough participants and could not proceed. It is likely this was in part driven by concerns regarding attendance at in-person events due to increasing rates of COVID-19 at that time.

People who attended were asked where they had heard of the opportunity to participate in the focus group. Those who told us heard from the networks below:

- **Direct mailing from the ALLIANCE (5)**
- **ALLIANCE website (1)**
- **ALLIANCE Twitter (1)**
- **Local Macmillan Group (Cancer Voices or Move More) (3)**
- **The Beatson West of Scotland Cancer Centre (2)**
- **Local patient group (1)**

3.2 Participant recruitment

Participant criteria sought consenting adults affected by cancer in the last three years, either themselves, or as a carer, family member or loved one of someone else diagnosed with cancer.

All participants were provided with a detailed information pack outlining the purpose and format of the focus groups to assure they could make a fully informed decision to participate, as well as a privacy statement, consent form, and an equality monitoring questionnaire which was optional for completion. Participation was opt-in and voluntary by returning the completed consent form as evidence that informed consent had been given.

3.3 Focus group design

All four focus groups were delivered online using Zoom. Each focus group lasted approximately 90 minutes, with between two and five participants at each. There was a facilitator (Scottish Government Cancer Policy Unit Clinical Advisor) who led each session, accompanied by two note-takers from the ALLIANCE. Each session was recorded with participants' consent for analysis purposes only.

Each focus group followed a similar format utilising a detailed topic guide covering introductions and scene setting, as well as specific questions with additional prompts and follow-up as required. The main questions asked of participants included:

1. **Can I ask how many of you have heard the term 'prehabilitation' before being asked to join this session?**
2. **In your words, what do you think this term means/how would you describe prehabilitation?**
3. **Definitions of 'prehabilitation': when you hear it described this way, what springs to mind?**
 - a. A process that occurs between a cancer diagnosis and the beginning of treatment (curative or palliative). It includes physical and psychological assessments that help understand current abilities and/or issues, and includes actions designed to improve physical and mental health and reduce the number and/or severity of future issues.
 - b. Advice, support and services offered to a person after a cancer diagnosis but before their agreed treatment begins. This includes assessment of your physical and psychological wellbeing so that the health professionals involved in your cancer care understand your current abilities and are aware of any potential issues. The results of your assessments inform actions to improve your physical and mental health to reduce the number and/or severity of future issues you might experience during or after your cancer treatment.
4. **Thinking again about when you or the person you support was first diagnosed with cancer, do you think you'd have engaged in prehabilitation if it was offered to you?**
5. **Thinking back to when you or the person you support was diagnosed with cancer, how do you think you would have responded to this offer?**
6. **Thinking a little bit more about how we could deliver prehabilitation, what role do you think digital technology has, for example websites, apps etc.?**
7. **Given all that we've discussed today, is there anything else you wish to say about prehabilitation that will help us design and deliver these services?**

3.4 Participant analysis

In total, 14 people affected by cancer took part in a focus group. All had personally had a diagnosis of cancer. Six people we spoke with had received a diagnosis of primary breast cancer, one of whom had a more recent diagnosis of secondary breast cancer. Two people had been diagnosed with leukaemia. Other individuals told us they had received diagnoses of lymphoma; cervical; and bowel cancer. Three participants did not disclose the type of cancer they had experience of – but two of those people did discuss that their diagnosis related to a rare cancer. Of those people who disclosed specific timescales since their initial diagnosis, these ranged from 2018 to 2021.

Equalities monitoring information was provided by 13 of the 14 participants. Of those participants who were happy to share their demographics:

- **Twelve participants identified as female, and one identified as male.**
- **Ages ranged from 39 to 65 with an average age of 53 and median age of 53.**
- **Eleven participants described their sexual orientation as heterosexual, with two indicating gay/lesbian.**
- **All 13 participants described their ethnic group as white, with 11 reporting they identified as white Scottish; one USA; and one Anglo Scottish.**
- **Eight participants reported they had no religious belief, with four indicating Church of Scotland and one Catholic.**
- **With regards disability, nine people advised they considered themselves to have a physical or mental health condition or illness lasting, or expected to last, 12 months or more; three did not; and one did not know.**

Four participants also discussed their role as an unpaid carer, all of whom described their extensive and substantial caring roles and responsibilities. Most of whom were caring for an elderly parent, sometimes as well as having their own parental responsibilities and/or other additional caring roles to support other friends or relatives, whilst at times coping alone with their own cancer diagnosis so as not to burden others. Other people told us about the impact of living with cancer alongside living with their own other co-morbid health conditions.

3.5 Thematic analysis

Detailed notes were taken at each session which were reviewed with reference to the audio-recordings of discussions. Notes were aggregated, anonymised and interrogated utilising qualitative thematic analysis methodology to identify key themes, which are reported in detail in section four.

4. Findings

4.1 Awareness and perceptions of cancer prehabilitation

a. General awareness

There was mixed awareness of the term 'prehabilitation', ranging from never having heard the term before, to educated guesses as to what it might mean, to some awareness.

“ I'd never heard the term before but it makes a lot of sense. Anybody that I've known who has had cancer that has survived has been someone who was in good health to begin with.

“ I think, for me, I kind of described it as being fighting fit. The fittest that you can be to take on an operation, possibly chemotherapy, radiotherapy, whatever it might be. Just to be the fittest that you can be... Being as active and as strong and as healthy as you can be prior to any treatment.



“ I thought it meant how you might be supported at the very beginning stage as opposed to after treatment which seemed like a good idea as someone who has just been at the very beginning stage.

However, it is worth noting that several of those people with some awareness of the term were directly involved in cancer service developments either professionally due to their work role, or through volunteer roles, possibly suggesting the level of awareness might be less so amongst the general public.

Introducing people to the term ‘prehabilitation’ also provided opportunity for participants to reflect on their own experiences, as well as consider whether they had received any prehabilitation support between diagnosis and their own treatment starting.

“ I think I would’ve made the time because I wanted to be in the best possible health. Nutrition wise, exercise wise to go ahead for my operation. So I would make the time to do that.

“ I feel like I got advice nine months down the line about physical activity, which I have taken up and I am enjoying. But nutrition wise and for your mental wellbeing, I didn’t really get any support at all.

“ People’s heads are in a mess when they get the diagnosis. So I think that idea of someone stepping in and, as far as possible, trying to tailor to people’s needs and just pushing people in the direction is something that certainly was missing in my case.

“ It’s not a concept anyone I met is comfortable talking.

“ From my experience, I can see how being fit and healthy does really help you through your treatment.

b. Definition

In general, people thought the term ‘prehabilitation’ and the definitions of cancer prehabilitation presented to them were too abstract, complex and clinical, although there was some limited support for the second definition.

“ I like this [second definition] better. I think it’s more human.

There was a strength of feeling that some of the terminology and phraseology being used was off-putting, confusing and anxiety provoking.

“ Just ditch it to be honest, even the name prehabilitation, I mean, you’ve just had a cancer diagnosis. What, are you going to sit and read all that? You’re not interested. You want to know the big stuff, you know, have it just a bit more human-centric, a couple of lines to say, you know, we’re here for you, you know, at the start of your journey.



Use of the word 'assessment' was also disliked by other participants. It was felt that the term 'assessment' had connotations of a 'tick-box exercise' and 'people with clipboards asking questions' that are perceived negatively.

“ I think just the word assessment. I think that would freak a lot of people out. Erm, I mean I've used assessments all my working life for different things in different settings. . . it's just the word assessment to me just kinda thinks, OK, is that me gonna be labelled I've got a mental health issue and then that's going to follow me through my journey and follow me when I come out the other side, erm, that's what's really glaring at me.

“ I'm drawn to assessments again... What type of assessments do they mean? I don't know if we have the capability to assess people at that stage, about their wellbeing.

“ The word assessment makes it sounds like there's going to be someone standing there with a clipboard asking you a whole series of questions, that you're going to have to fill in a questionnaire and give them all this detail.

“ Reading that as a patient it just makes you feel, OK, right, they're going to get me to do a questionnaire and tick more boxes.



Other terminology participants didn't like included reference to 'abilities' which triggered anxiety for some that their cancer diagnosis would result in disability or things they could not do.

“ The bit that sticks out for me a little bit is your current abilities. There's just something about that that makes me think, er, that for me, like you're diagnosed with cancer and suddenly you're not able to do anything . . . 'abilities' suggests you're maybe, there's things you can't do, which might be the case, but suggests you're suddenly disabled because of a diagnosis.

There was also much consensus that any description designed to help people better understand what cancer prehabilitation was, needed to be much less clinical.

Suggested alternative descriptors to the term 'prehabilitation' included using language such as:

“ How can we help you be the best prepared you can be before your treatment starts?

“ I think Macmillan calls it preparing yourself for your cancer treatment or getting ready for your cancer treatment and that's the kind of language, you know.

“ Like an athlete getting ready

“ Pillars of wellbeing which to me are your mental and emotional health, your diet, supplementation, exercise and movement and sleep, and if you can address all these areas you'll be putting yourself, er, you'll be as healthy as you can be.

People also suggested that it would be beneficial when describing cancer prehabilitation to also provide real-life examples of the activities or interventions this would entail to help people better understand what it would mean for them.

Others suggested that language generally had to be much more motivational to support a 'let's fight this' mentality. Whilst others raised the importance of a need for early interactions and conversations with clinicians to emphasise 'the humanity of what people are going through', with many people telling us they felt the human-side of their experience was lost or forgotten as much of their care was very clinically or medically focused.

“ It feels like the language of business or the language of industrial healthcare. It doesn't feel like you're a human being, and we care, and we want you to be as supported as you can be at the beginning of the process, during the process, and after the process, whatever that process may look like.



4.2 Accessing cancer prehabilitation support

a. Responding to the prehabilitation offer

Some of the people we spoke with could see the value of cancer prehabilitation, but this was not universal. We heard some reasons why the prehabilitation offer might be considered negatively by some people.

“ If I got a little leaflet, right, that talks about my physical health, my diet, you know, psychological, I’ll be honest with you, I would be incredibly insulted by that, and the reason being I would just think, so you want me to do a couple of handstands, eat an apple and then do some meditation and it will be all fine? For someone like me who was incredibly fit, goes to the gym every day, eats incredibly healthy, that would be insulting to me to receive something like that.

Some participants felt that prehabilitation should be couched in ‘non-clinical’ terms as part of a more holistic support offer in partnership with other agencies such as third sector partners or as part of peer support.

“ I think it would be helpful if they were set not in a clinical setting, so they were offered in, maybe, your local Maggie’s Centre, er, if the hospital has links with them, or a Macmillan site?



b. Who should introduce prehabilitation

There didn't appear to be particularly strong views on who should introduce the concept of prehabilitation to patients and their families.

“ For most patients I don't think they mind who provides the support, what umbrella it comes under, that's more where it's a political side of who is doing what, but for us we just want somebody there and would like services to be streamlined.

Some people felt prehabilitation should be introduced by their consultant or cancer nurse specialist to emphasise the importance of the interventions in assuring readiness for treatment, including benefits to the clinician as well as the patient.

“ There's something about honesty, and being open about, and really saying, if you do this, this will actually help the surgeon.

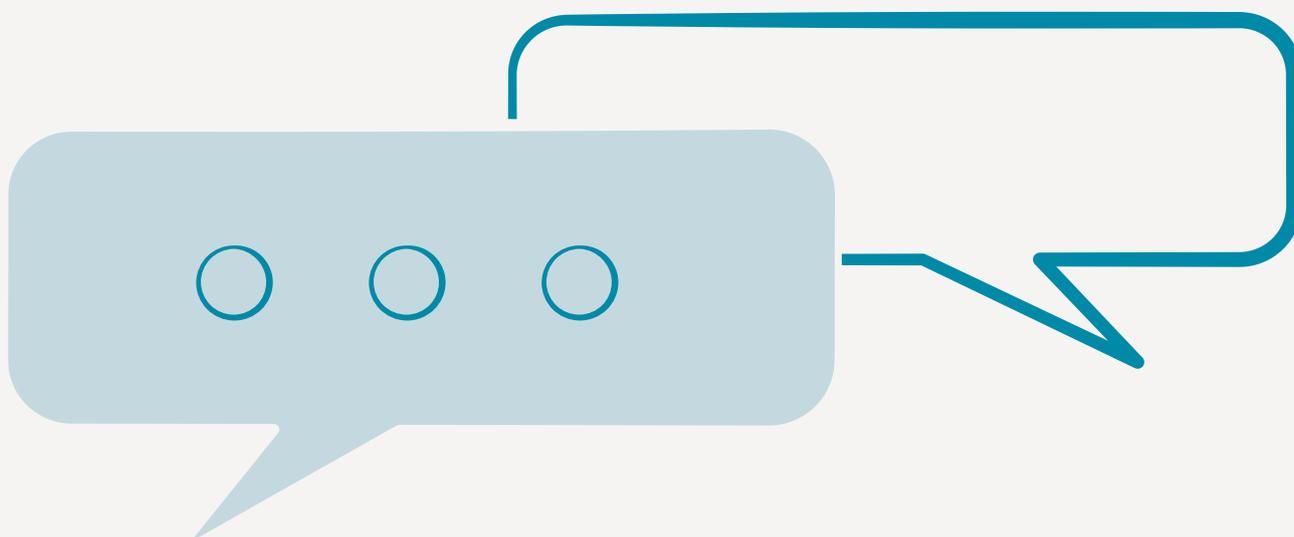
Other people told us of concerns given how busy their clinical teams appear to be, and how this might impact on a clinician's ability to offer prehabilitation support.

“ I would think probably not the oncologist because of their workload and priorities. I had kind of been thinking it would be a nurse. But the idea of it being a peer is interesting. I think if the introduction was made through the team you're saying then that might work well. I suppose, also I'm thinking, would they have the answers to all the questions. They may not have all of the answers to all of the questions. That would be worrying to me as an individual.

However, there was general consensus that the offer and discussion of what prehabilitation will entail should be given verbally, at least initially, from a person involved in the person's care and not be solely reliant on people newly diagnosed with cancer reading leaflets or other resources. There was also a strength of feeling that this discussion take place face to face as opposed to a telephone call.

“ I think it needs to be from an actual person... The diagnosis pack that you get has lots of really valuable information but you're not taking it in. That was the wrong time for me. I knew about the programme, I knew I should be fit, I should be well. But I was not focused on that part of it. I think if it had come in the form of another leaflet or piece of paper, again, I don't think I would have paid that much attention to it. Whereas if somebody had said to me, you get fit and well and get ready for this operation, I would've listened. And I would've said how do I do that? Where do I go for this? Give me more information.

“ There's tons of information they give you and it's all very, very helpful. And it's pretty clear. And there's lots of resources out there. But it's the personal connection that's the important bit.



c. Timing of interventions and continuum of care

There was strong consensus that prehabilitation support and services need to be an integral part of a person's longer-term rehabilitation journey within a continuum of care, with interventions and support available before, during and after cancer treatment.

“ It's not just about the prehabilitation, it's got to follow through. It's got to be something that starts when you're diagnosed and keeps going through all the different stages of where you are, during and post treatment even if it's three or four years down the line.

In particular, there was a lot of concern that reference to 'prehabilitation' as interventions 'pre-treatment' was too narrow.

“ There is a need to bookend this at either end as I was really surprised at how adrift I felt at the end of treatment.

Most people we spoke with felt the timing of psychological, physical or nutritional interventions would benefit people at different stages of their care dependent on people's individual needs and circumstances. People felt that physical and emotional support would have benefited them not only before treatment, but also during and long after treatment ended.

“ It sounds fine to me other than the part where it's saying it's about, er, pre-treatment. And I know that this talks about prehabilitation but my concern would be it's only available before you start treatment and not everybody is going to be in the right place to take on board everything at that time, so would it be available, er, pre and post treatment?

“ I’d like to see this after treatment. I’d like to see a physical or mental assessment after it as you don’t have time to process all this as literally you’ve got your plan and you’re going for it, you’re signed up for it and you’re on your way.

There were also two opposing views on the feasibility of prehabilitation interventions prior to treatment. For those whose treatment followed their diagnosis very quickly, some people could not see how they could have feasibly accommodated any interventions to support any improvements in their physical or psychological health within the tight timescales between diagnosis and treatment commencing.

“ It wasn’t discussed or mentioned in my treatment. There wasn’t really much time. If I wanted to get fit before my surgery I only had three weeks.

For others, they would have welcomed any kind of prehabilitation support offered to them, primarily to provide them with a distraction from their own worry and anxiety about what might happen in the future, and address feelings of being in limbo, isolation and having no-one to talk to about their concerns.

“ I think it would have occupied your mind at times, doing other things. Because I felt the 12 weeks prior to my operation I just worried the whole 12 weeks. About what was coming, how to deal with it.

“ For all it was only two weeks [from diagnosis to treatment], they are the worst two weeks, because all you are thinking about is the worst. You have no real contact with anyone. And I think if I had a programme to focus on, that somebody had said to me you need to do this for your best chance at getting well and getting well quick, I would’ve went absolutely.

“ I was diagnosed just before Christmas. My operation I was told would be about a month’s time and it went exactly in a month’s time, but during that time I was sort of left in limbo, I was left alone. . . so something during that time would’ve been helpful.

d. Preferences and barriers to access

Whilst there was a definite preference for face to face services, location of such services was a source of concern for some people we spoke with.

“ I would be hacked off if I had to go to different places across town. I probably wouldn’t go actually.

“ I couldn’t drive at that point either. My family were all working so how do I get into Glasgow? I could hardly just jump on a train when I couldnae even walk

There was a perception that cancer support services tend to be centralised in the central belt with less services available locally across Scotland – especially when living more rurally. People told us of the practical difficulties and barriers they face if there is an expectation that they need to travel – particularly when very ill due to their cancer symptoms and/or effects of treatment.

“ When you’re sick, when you’re tired, when you’re emotional, when you can’t drag yourself off the settee, the prospect of getting in a car, and driving up, and driving around for 20 minutes trying to find a parking space, er, you know, it’s just too exhausting a prospect.

“ I think it would be different for different people. I think locally though... What kind of struck me when I was getting my chemotherapy was the distance that some people were having to travel to get there. Particularly when you're feeling ill.

Whilst people fed back that prehabilitation support services should be provided locally within their own communities, there was also a view, particularly in relation to the potential different components of prehabilitation support (i.e. physical activity, nutritional support, psychological support from different professionals) that it may be beneficial if these were all delivered collectively in the same location.

“ I would have found that a benefit personally... A central point where you could get all of your information.

There was also some discussion that prehabilitation support should not take the form of a rigid programme of activity, but requires to be a flexible and adaptable menu of support that can flex dependent on people's individual needs, with one participant describing a barrier to their participation would be if prehabilitation was perceived as 'just another appointment'.

People also described the reality of accommodating multiple appointments within their oftentimes busy life schedules – many people juggling full-time work commitments, their own family commitments, caring responsibilities, as well as multiple clinical appointments post-diagnosis. Whilst prehabilitation support was viewed positively, there was undoubtedly a challenge posed for people to accommodate additional interactions and interventions.

Yet, people felt strongly that prehabilitation support should be offered face to face wherever possible – primarily due to a perceived lack of emotional support currently and a perception that prehabilitation support could potentially fill that gap.

“ I always think face to face is better because then you can see a proper reaction. You can see how people are feeling. I think a telephone call is okay in the circumstances but then I don't think there's anything to beat that face to face. It can evolve after that. Whereas I think a telephone call is very matter of fact. And I think you don't see the true picture of how someone is actually feeling.

4.3 Perceived prehabilitation support needs

a. Psychological and emotional impact

The most recurring theme by far during all discussions was the need for more emotional and psychological support to be made available due to perceived unmet emotional support needs throughout all stages of people's experience of living with cancer.

“ That was the thing, I had all the medical information, all the, you know, this is the kind of tumour it is, you know, this is what is going to happen, these are the drugs you'll be getting, you'll have, well, the physical side effects. But nobody, nobody prepares you for the emotional side of things, and that was the thing that really floored me.

“ When you first get diagnosed and hear that word, my immediate reaction was, not to anyone in particular, but just to myself, am I going to die? What's going to happen? It's that sudden fear of, you know, suddenly everything's out of control. You don't feel you have any control of what's happening at that particular time. You're just all over the place... [Prehabilitation] would have been very good to have in the initial stages when there's that fear.

Interestingly, there was mixed feedback on when that need for emotional support first became evident and most pressing. For some people the need for emotional support was immediate and very soon after their initial suspicion of cancer. For others, it was immediately following diagnosis. But for others, it was at various stages before, during, after or long after their treatment.



“ At the time going through treatment I just wanted someone to reassure me it was normal to feel the way I was feeling. Nobody prepares you for that. They prepare you for all the physical side of things, but nobody said there will be days when you just feel like you can't deal with it any longer, there will be days you're on the phone to your team saying you want to stop this, and I know now that's quite normal, quite natural. None of that is explained to you.

“ I would like to know things about what happens when you go into hospital in terms of a psychological aspect, things that you would never think about. Things like, which really upset me, was when I went into my ward, I looked at people that were later down the line in my treatment than me, somebody who was the same age as me, who were at death's door. I wasn't mentally prepared for that. I didn't know. I just thought I was dealing with my own wee battle and that was it. I was forming really good relationships with people in wards and stuff like that, and then the next night, you know, a trolley is coming up to take them away because they've passed away. These are all the battles that are going on in your head.

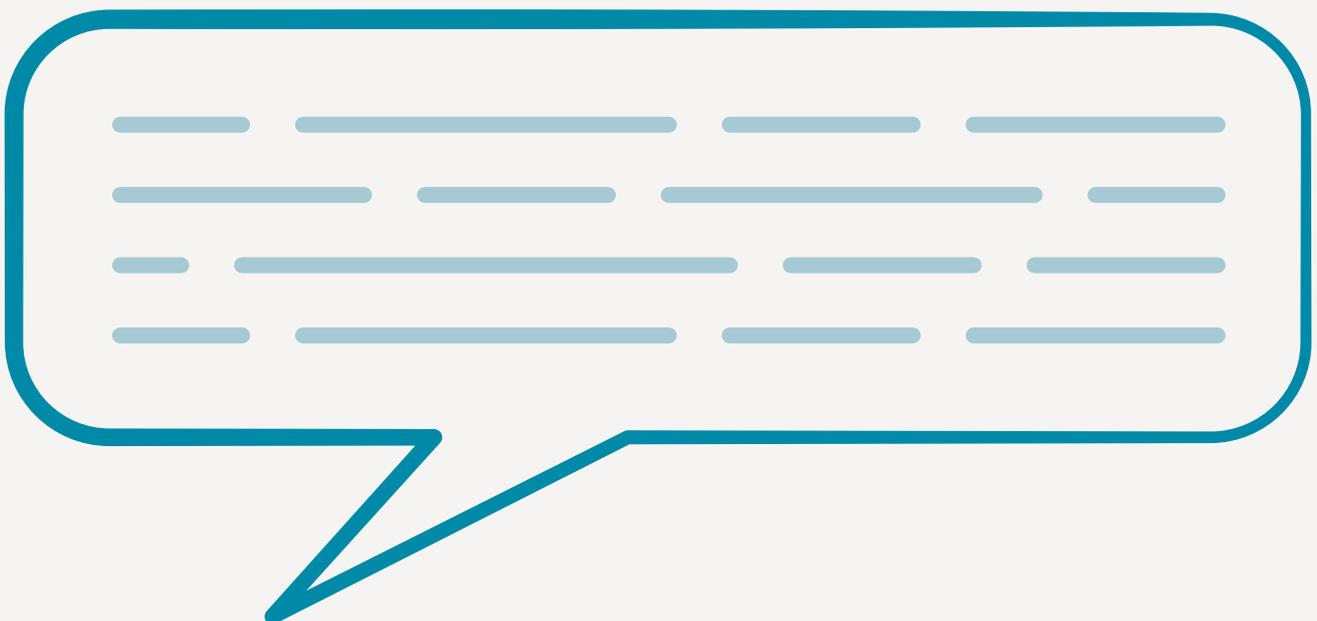
“ The psychological aspect of it probably hit me after my treatment finished, which I think can be quite common.

As such, there was overwhelming support for additional psychological support to be made available as an integral part of any prehabilitation support offer. However, concerns were again raised around continuity of care and assurance sought that psychological support would continue to be accessible not just at diagnosis, but throughout treatment and beyond.

“ Things hit you more once you’ve come out the other end, when everybody then, even your consultants and your specialist nurses, right, we’ve done our bit, and then you’re left.

“ I think there has to be recognition that the psychological effects can happen at different stages and it can happen years after you’ve been diagnosed, you’ve been treated, you’ve been given the all-clear. The psychological impact is always there, it always will be, but it just takes different shapes at different times.

“ I don’t think I was mentally okay. It’s only recently when I’ve finished treatment that I’ve stepped back and I know you have that kind of post trauma evaluation. But actually, I was on such a conveyor belt that anyone could’ve done anything to me and I think I would’ve just went okay, fine.



b. Physical health and nutritional support

Positive support for potential prehabilitation interventions around physical activity or nutrition needs was mainly forthcoming from people who had experienced their own physical or nutritional difficulties or challenges, either due to the impact of cancer symptoms pre-diagnosis or due to identified issues prior to their own treatment starting.

“ I was fairly fit before. It felt like my GP’s office didn’t want to see anyone because of COVID. It took four weeks of going back to them and saying something’s wrong until they finally took blood and that sort of kicked the whole process off. By the time they had started to do serious biopsies and things I had already lost 10 kilos of weight. So I was really getting more and more unfit. I was really weak, I was really tired.

Some people we spoke to struggled to see the benefit of interventions to help them improve their physical or nutritional health prior to their treatment. This was in part due to the tight timescales many had experienced between diagnosis and treatment making them question the value of trying to do anything to improve their health, whilst for others it was a perception that they were already fit and in no need of additional interventions.

For others, the suggestion of needing any kind of physical or nutritional health improvement intervention triggered guilt that their poor physical health may have contributed to their cancer diagnosis.

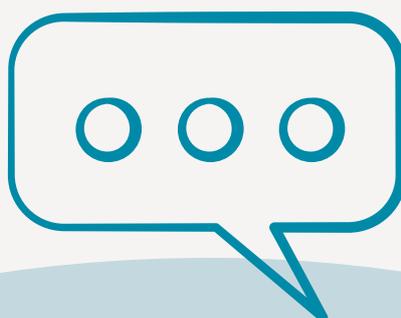
“ When I think back to comments about my weight, cause I am still overweight, and I don’t want to feel bad about that, cause I feel it’s bad enough thinking God I’ve got cancer, but feeling bad for your physical status, is a very tricky thing to communicate and discuss . . . thinking oh my God I caused this, it’s all my fault.

For some, it became apparent during discussion that any reservations were most likely due to a lack of awareness of the need to consider their physical and nutritional health from the outset e.g. lack of awareness of the potential impact of and/or contraindications during treatment with systemic anti-cancer treatments and the resultant impact on physical or nutritional health.

“ I had real struggles with my weight because I didn't have weight to lose when I started and I've lost a stone in weight and I didn't understand about the whole chemotherapy metabolising through, so it's just where is the repository for that information? That would've been really useful for me.

One person also told us about the insensitivity they experienced from staff involved in their care when discussing their weight loss.

“ Some of the attitudes are really, really awful. I was talking to the people who were getting me to sign my consent form for major surgery. There was a clinical nurse specialist, no idea what she was for, or why she was there, I thought she was a chaperone. And a doctor. I happened to say, as they muttered something about weight, and I said well, I am actually four dress sizes smaller than I was before I retired, and they started laughing. And I said, sorry? Sorry? And they said, oh you've seen nothing, you're fine, and I thought now I know the mindset you are going to have if you had met me when I was four sizes bigger.



c. Multi-agency sources of support and integration of care

The need for services to be better integrated was a recurring theme. People reported that the current system feels disjointed and compartmentalised with different professionals and different services working in their own silos.

“ It was a conveyor belt, and some bits are less conveying than others, er, and sometimes you feel you are just a cog in the machine.

“ There is a tendency, particularly with breast cancer, that very much you’re on a conveyor belt and it is assumed everything will go to plan, and you’ll just follow the plan exactly and you’re not really perhaps warned that things don’t go to plan.

People gave examples of when things went wrong due to disjointed service delivery or poor communication, highlighting a need for all services and support structures involved in a person’s care to communicate better with each other.

“ I think a phone call in the early days is most beneficial. I received a letter from Macmillan which was awful formal and too difficult to really figure out what they were offering, and it was one more thing to do and it sat there for months and months which is a shame as I kinda missed out on support early on which would’ve been useful, and I think a phone call or more personal contact early on would’ve been great.

“ I think, er, for me there’s something about being a bit more joined up between what’s happening in the hospital and your GP . . .we’re talking about a journey but it doesn’t feel very joined up.

“ Because of those seams [between services], things get missed. I was never put on a shielding list until I said to the secretary of the consultant... It’s the connections between all of the different components that make it challenging. I can understand that you would need to have something that follows you so that all of these people who treat you know what your situation is. And it needs to be documented in some way.

People were generally supportive of a multi-agency approach, acknowledging the benefits of having access to services delivered by statutory service clinicians and third sector organisations.

Some people felt there was a need for greater acknowledgement that grass roots and community-based charities should be seen as just as important as larger national charities, with someone describing the role their third sector organisation had played in supporting others and filling what they described as ‘gaps’ in specialist cancer support.

“ We’re finding as well that we’re getting, we’re having to fill the gap, as a charity, for patients who’ve just been diagnosed with cancer and also who are going through treatment because they’re not getting that support from their specialists within their treatment centre.

There was also a desire for greater access to peer support and companionship from other people affected by cancer as part of any prehabilitation support offer.

“ Although I’ve said that I really want that professional input. Having gone through it and now that I’ve helped others... From the honour amongst thieves, that you’ve got that familiarity with someone who’s been through it.

“ Any contact that you could have with people who have been through it would be brilliant.

d. Other support needs

When designing prehabilitation support services, people described a range of other factors that they felt should be considered to better meet the needs of people newly diagnosed with cancer.

“ It’s absolutely exhausting trying to manage a condition that’s going to be here for life with the prospect of life being foreshortened. And having to work through this myself with no guidance is really hard work and such a waste of my time and energy when everyone is reinventing this wheel for themselves. There’s got to be a better way of supporting people.

Assuring timeous access to prehabilitation support was particularly important to people due to the oftentimes tight timescales between diagnosis and treatment starting.

“ Macmillan contacted me through the local authority and had set up a meeting but then we went into lockdown and that fell by the wayside. The representative from Macmillan who works with the local authority did organise counselling for me but I waited three months, so I was well finished treatment by that time, which was fine and possibly more beneficial.



People also spoke of a desire for out of hours access to support from a professional involved in their care.

“ During the week Monday to Friday I could phone the hospital and speak to my oncologist or my oncology team, nurse or whatever if I wasn’t feeling well or anxious about something. But the minute it comes to five o’clock on a Friday, that’s it, and that’s you until a Monday morning. And I’ve spoken to friends about this, close friends who went through treatment at the same time as me, and we used to call it Freaky Friday.

People also asked for telephone helplines to be staffed. People we spoke with told us about times when they called key contacts for support (e.g. cancer nurse specialists) and how they often encountered voicemail and waits for call backs – sometimes hours or days later. People discussed the benefit of having their concerns and questions addressed timeously as opposed to long waits for return calls manifesting additional anxiety.

“ Yes, the breast cancer nurses are there, they say they’re there to help you but any time you phone them they’re always in a clinic or busy with something else and they can’t help you. They always do phone you back, but you needed that support right then.

“ Someone you can build up a relationship with and contact easily. The navigation system up in Aberdeen is brilliant. You speak to a human being and they’re warm and friendly, they’ll help you with anything, whereas my service is you phone, you get an answerphone message which basically says phone somebody else if for an appointment, phone somebody else if for this, phone somebody else if for that, and it’s really off-putting and confusing.

Some people asked for greater ease of access to their health information, including copies of care plans and the results of their assessments or reports, for both the patient and all clinicians involved in their care.

“ Easier access to reports online. There are portals around used in some places in the NHS so patients get the report almost as soon as the clinical team do if they wish to access them. At the moment I have to go through a freedom of information request every time I want to see a scan.

There was also an ask that professionals consider how they can keep the burden of completing assessments and questionnaires to a minimum.

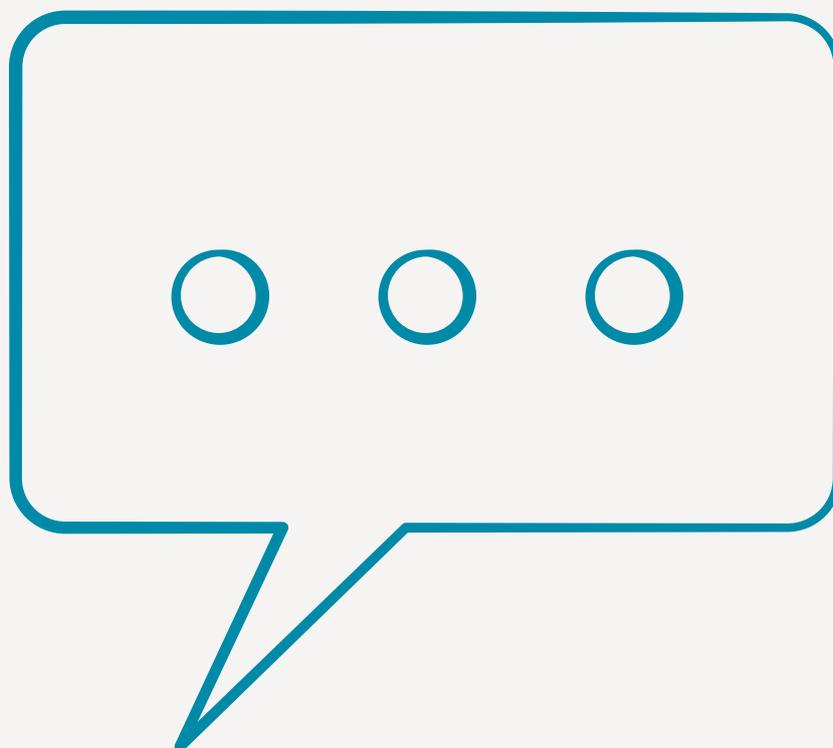
“ To keep going I had to fill in a 12-page physical activity questionnaire which was so ridiculous. They wanted to know how many minutes I had spent walking outside, do not include standing, sitting, driving or working. I'll hold it up. It was just crazy. So please if you want us to take part in stuff like that, and if we want to take part, make the checking back stuff much more simple. I mean I sat and cried over that one day cause I thought how on earth can I tell how many minutes do I spend on active housework? I mean, please.

A recurring theme was the perceived benefit of having access to a single point of contact throughout their cancer journey who gets to know both them and their families. People felt that such a role should be introduced to them as part of the prehabilitation offer as early as possible following diagnosis.

“ As long as people are listened to, and they know they have got something there where they can get in touch with people or know there's a regular check-in, would be a big, big benefit.

People intimated they felt the role for that key contact should be clearly explained to them and offer them protected time to discuss how they feel beyond their clinical needs, enabling an opportunity to offload concerns. Someone who pro-actively keeps in touch with people and offers them reassurance, during an oftentimes long and complicated journey. Someone who would step in from day one to identify and tailor support to better address people's individual and sometimes unique physical and emotional needs.

“ Had I been given the opportunity to sit down with somebody, a nurse or somebody to say, right, look, you know, this is what's going to happen but you need to consider, you know, you're going to feel like this, you're going to feel like that, things might be tough, but this is where you can go for help if you need it, this is who you can speak to about this, this is who you can speak to about that. Some kind of joined up thinking.



4.4 Role of information and digital technology

a. Access to information

People were generally very accepting of the need for, and benefits of, written and other information to help them self manage aspects of their own care. However, there was some feedback around information overload following a cancer diagnosis.

“ In the early days of diagnosis you’re hit, you’re stunned, and you’re going through so many tests and appointments it’s hard to take onboard a lot of extra information. You’re still trying to come to terms with what’s going on and trying to juggle all these appointments that’ll be coming up so I think what would be most helpful at that point is a cancer nurse who is there to provide you, signpost you, to local support services, to the pillars of wellbeing, to be there to offload to, but not in a deep way.

People also spoke about the importance of being able to access their own health information, with feedback on how daunting it can be leaving an important appointment with nothing in your hands to refer back to, meaning people have to rely on their own memories after having being given sometimes traumatic news – compounded by not even having a family member present to help with recall as a result of risk mitigations during the COVID pandemic.

“ When you’re first diagnosed you get nothing in writing. These are life changing experiences and you walk out of that room without a piece of paper explaining to you what your diagnosis is.

“ My medical certificates from both the hospital and GP didn’t say cancer. It stated a gynaecological surgery so . . . I’ve got nothing in writing telling me I’ve been diagnosed with cancer.

We also heard of instances where a lack of easily available, or lack of easily accessible, information impacted negatively on people, particularly for those people diagnosed with a rare type of cancer who struggled to find any information specific to their own information needs.

“ Because it’s a rare form of cancer as well there is very little out there I can access . . .so just to have someone I can go to. There is a lot of charities particularly in the Glasgow area that doesn’t really help me because I work full-time. . . I do not have the time to go up to Marie Curie or any of the bigger ones so for me that local support is crucial, and the fact that it is a rare form of cancer as well, then I’m kinda struggling a wee bit, er particularly emotionally, trying to get my head around what is it, why has it occurred, why has it reoccurred. So, yeah, I’ve got loads of questions and because of the type of person I am I don’t want it given to me in clinical or medical terms which I had last week, as it’s my body and I want to know what’s going on.

“ I know I need to look after myself. I need to keep myself as well as I can do because I’m facing, well, I don’t know what I’m facing around the radiotherapy and chemotherapy as I’ve never had it before, but I know at the end of that I have a surgery, or possibly a major surgery, that’s going to completely change my life, er. So, I need to keep myself both physically and emotionally as well as I can but that’s easier said than done when you’ve no access to information.

b. Online information and tools that aid self management

A recurring theme was the need for more support and signposting from professionals to help people identify trusted sources of online information – many people reporting the challenges they had personally faced when trying to find balanced and accurate information online following their own cancer diagnosis, and the impact of ‘horrendous’ and ‘misleading’ stories and misinformation they sometimes encountered.

“ And looking for myself I came across a lot of the ‘quack’ websites and the scary information, er, and I dropped it until last year and then thought there’s got to be a middle ground and started researching again. But again, I wasn’t even signposted by the major cancer charities towards this sort of information.

“ I think if you were advised what were the correct websites because I think there is so much information out there that is misleading. I was lucky that my GP gave me a couple of sites to go to.

“ There’s a lot that you’re dealing with and they tell you lots of stuff, they do provide you with a lot of support at that time, er, but then you’re kind of, then you have to go off and learn some more stuff and try not to look at Google, they say not to look at Google, but then it gets you all wound up about stuff.

“ Every time I come up with something I have read on the forum [for my condition], they [my clinical team] get frustrated with me. Stop looking at the internet. Your condition is specific to you. I realise I perhaps read too much into things.

Therefore, people generally welcomed digital developments that would improve access and/or signposting to trusted sources of online cancer information – particularly if the information could be tailored to their own specific cancer and their own individual information needs and circumstances.

“ They need to be proactive in directing people to health and wellbeing activities that we can undertake for ourselves and they need to be pro-active, because as patients we’re really passive, we think the NHS are going to tell us what to do and they’ve not mentioned X, Y and Z so that doesn’t matter.

“ You don’t have to reinvent the wheel here, I mean, there’s so many amazing resources out there, it’s just really about signposting.

However, some people also told us of the challenges of accommodating online self management activities around all their other commitments.

“ I mean there is a Maggie’s but I’ve not been there, er, and they’ve got a Moving Forward course but it’s online and I really struggled with that cause I’m working full-time.

People also felt they would also benefit from continued access to a person or single point of contact who could help guide them through online tools and answer any questions.

“ When I was first diagnosed, it was the websites I was going to, to try and get as much information as I could. Sometimes, I think too much information on the website can be misleading. And if you had someone to rein you back in a wee bit, rather than let your mind go.

“ I felt I was floundering and not sure of what direction to go in and what to do. And if there had been someone there to advise you and guide you I think that would have been a great benefit.

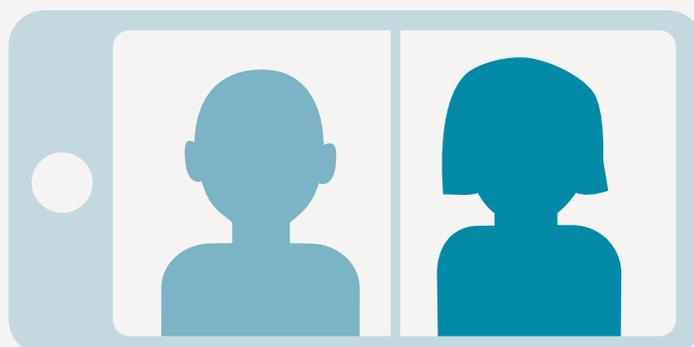
c. Digital tools that support clinical interaction

There were mixed views on using online tools for clinical and other types of interaction e.g. group support.

Some people did see added value in having access to digital tools to support clinical interactions, particularly from those people who had routinely experienced barriers when accessing more traditional face-to-face services.

“ One thing around inclusion as someone with MS. There’s been points which in my life with MS I’ve been bedridden. Points when I’ve not been. And something that the pandemic did draw out from the community of the chronically ill was how much more access people had to support services once they were put online. So I guess what people in that community are hoping for is that it doesn’t just go back to everything being physical settings.

“ Er, video appointments? And again these can be done in some parts of the NHS, but if we can’t meet face to face then, erm, can we not have some video appointments?



Other people emphasised their desire for face-to-face support from a professional as they felt it was invaluable and should not be lost – with a desire that any digital developments be in addition to face to face and in-person interactions, as opposed to instead of.

“ I’m not a big fan of speaking on the phone. I’d rather meet with people in person. Erm, Zoom works as a sort of alternative but it’s not the same as having someone there.

Whilst people generally ranked online communication tools (such as NHS Near Me or Zoom) above telephone conversation, again, people said that nothing compared to the personal connection of meeting face-to-face.

“ Zoom is definitely better than telephone conversations but I still think if there was a face to face... But if you couldn’t do the face to face then I think this is a lot better than nothing at all.



4.5 Wider themes for consideration

a. Communication and relationships

There was a lot of discussion about communication and relationships with health professionals – particularly where there were perceptions of lack of communication and/or breakdowns in communication or disjointed care.

One such theme was the tendency of health professionals to assume greater levels of understanding, leaving patients confused and with lack of clarity on what had been discussed with them.

“ One of the oncology nurses is very clinical, very medical, and even when I said that’s as clear as mud, I think I need to go for a class in anatomy and start googling some of these big words that you’ve given me, er ‘oh yes, it’s a lot to take in’. Absolutely no empathy whatsoever.

People told us that they felt their health professionals were often not available when needed, with evident capacity issues and time pressures with no time to have in-depth discussions. People were therefore reluctant to burden their clinicians with their non-medical concerns, oftentimes leaving them with no source of support – particularly when in emotional distress.

“ You look at all those strained, tired people rushing around, harassed witless, and feel sorry for them because their time is so precious, and, you know, you can see that second hand going around when you ask yet another question and they go, oh God, you know, please spare me from a questioning patient.

There were also several references made to the role of the cancer nurse specialist as people’s main point of contact following their diagnosis. However, people reported mixed experiences.

“ When I was initially diagnosed, erm, I was advised that a nurse was going to come in and sit with me, and she was introduced to me as a sort of liaison, if you like, which was great. But then as the chat went on with the consultant, I looked at her and she just looked lost completely, she’d never been in with someone being diagnosed with Leukaemia, so when we came out she was like ‘oh my God are you OK’ and I thought that was a bit unprofessional, but that was that, but from that aspect it just looked as if a box was ticked. My experience after that was I never heard from her, you know, I was given her mobile number etc, tried to get in contact with her, and it was just blank, nothing was there.

“ I just felt I had nothing apart from the telephone calls from the cancer nurses. And they’re very very busy. Which you can totally understand.

“ It’s great on paper that you’ve got a specialist nurse, but the specialist nurse’s workload is massive so they don’t always follow-up and patients are left in limbo.

However, examples were also given of positive relationships and interactions with cancer nurses and other health professionals, and what factors made for good patient-clinician relationships.

“ She said it was important to have these discussions face to face but thanks to COVID we can’t do that just now. Very empathetic, very understanding. As much as she could transferred as much of the clinical knowledge into plain English for me. I was able to sleep that night if I’m honest, whereas the night before I couldn’t.

b. Impact of caring responsibilities

Those people who went into detail about their family caring responsibilities described challenging circumstances when trying to juggle their own appointments as well as their caring responsibilities compounding feelings of guilt and a desire not to worry others – oftentimes hiding their cancer diagnosis from the person they care for.

“ For many years I have been the sole carer for my mother, whose health was deteriorating rapidly. And I felt that, because of the relationship I had with my mother, I had to conceal what was wrong with me

People spoke of their worry and anxiety over what would happen to the people they care for should they, as carer, be incapacitated or hospitalised for treatment – often having no-one involved in their own care who they felt they could approach to discuss these concerns with.

“ I am also an only child. I have a husband. I have my dad who is 90, who lives with me, who also had cancer about 15 years ago. But is doing quite well and is partially sighted. But one of the things that really upset my dad was the fact that I had been diagnosed as well. And he was very much dependent on me and worried about the consequences of that.

Others told us about the challenges of dealing with the death of their loved one who they cared for and coping with grief whilst undergoing cancer treatment, with limited recourse to emotional support.

“ My mother died just before Christmas, the same day I had my first Beatson appointment. And, all that time, that was my priority. So I had no focus on what was wrong with me at all.

c. Family support needs

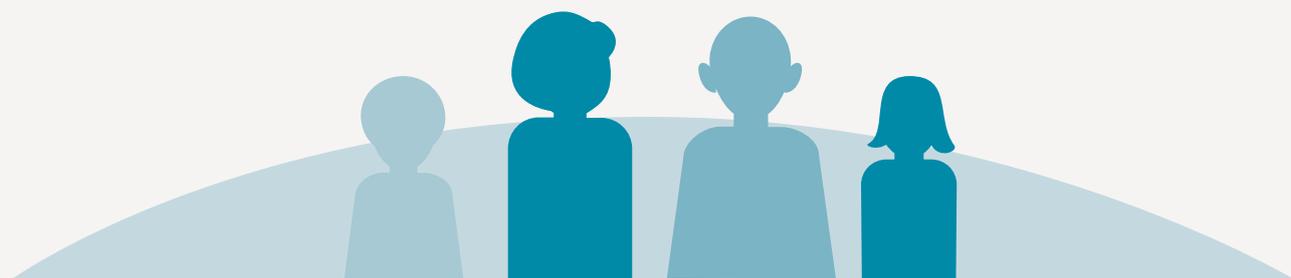
There was a strength of feeling that wider family members also have support needs – particularly with regards to a need for psychological support.

People felt strongly that family support should be integral to any prehabilitation service offer to assure early referral to support for family members who are also impacted by a cancer diagnosis.

“ The only thing I would suggest is that it’s really important that the family is supported as well. Not just the person who is being treated. Sometimes it can be even worse for them. And they can have other things going on in their lives. My partner’s mum has been very ill... So she’s got a full plate... Anything to support everyone involved would be really good. And prepare them emotionally, particularly. That was the hardest part for me, knowing how hard it was for her.

People also felt the gap in family support had widened and had been compounded by family member exclusion from clinician interactions due to COVID mitigations.

“ All of the information they were giving me, I had to relay to (my partner). I eventually asked the doctor if they could phone her because she was getting the information second hand from someone who was sick... They explained that normally she would’ve been in the hospital the whole time talking to them... When everything shut down, that was one of the things that was lost.



d. Impact on working life

Whilst some of the people we spoke with had retired or given up work, many had been and continued to be in full-time or part-time employment throughout their own journey living with cancer. Being able to maintain full-time employment was important for most, and a concern for some – particularly financial worries if unable to continue in full-time employment, or due to lengthy periods of sickness absence.

“ I work full-time which has caused major financial worries.

Moreover, several people were juggling their working life alongside their caring and other responsibilities, whilst also struggling to find time to attend their own healthcare appointments and cope with their own ill-health – sometimes alone so as not to burden their loved ones.

“ I work full-time. I’m knackered by the time I finish work at the moment, you know, so just trying to find the time to sit down and read a book, and if reading a book is it plain English or are you going to have to sit with google next to you so that you can see, right, what does that word mean, er, it is a minefield, an absolute minefield.

e. Impact of COVID-19

All of the people we spoke with had experienced some aspects of their cancer care during the COVID-19 pandemic.

“ All of us, more or less, have been through our experiences, or are going through our experiences, at a really unique time, er, when the health service is under so much pressure and, you know, you wouldn’t have imagined a time when you couldn’t just phone up and get an appointment with our GP in person. It’s all these things come together in a perfect storm almost, and, you know, we’ve kinda been at the centre of it. In some ways we’re in the worst case scenario here.

“ The fear of the virus out there, from the media and your own oncology team, kept reminding you that if you indeed get this there’s a very good chance you won’t survive it.

People told us of service changes as a result of COVID-19 that had impacted negatively on their experience of accessing cancer services.

“ The complications of my journey were mostly due to COVID.

“ Because it was early on in COVID, I think the NHS were still figuring out how they were dealing with people. So things like being visited in the hospital and stuff like that became really complex. So it made it difficult for communication with my partner to be involved in the process and to understand what was going on.

“ COVID had quite a lot to do with it and the fact you were on your own for everything. Nobody was allowed to attend anything with me.

Living and coping with COVID-19 had also compounded already higher levels of anxiety, but again oftentimes with no or limited sources of emotional or other support as availability of other services had also been impacted upon due to COVID-19.

“ I haven’t seen anyone since my operation last September because of COVID. That worries me a wee bit because I haven’t had the personal care, I suppose. It’s always just been telephone discussions.

5. Discussion

The offer to participate in cancer prehabilitation interventions was welcomed by most people affected by cancer we spoke with. However, language and terminology need to be accessible and person-centred if to be an attractive proposition for people.

People indicated a preference for local and face to face services but did perceive a role for digital tools in assuring access to the information they need. Timing of interventions needs to be flexible and adaptable to people's holistic needs and different experiences, with assurances sought that support structures and services will be available from diagnosis, throughout treatment and beyond.

There was huge support for increased universal access to psychological services, with some positive support for interventions to improve physical and nutritional health pre-treatment, where time allows, and a need can be evidenced.

When designing interventions, people wish interactions to be less clinical and more person centred, with discussions couched in terms that take better account of their levels of health literacy. Access to an identified dedicated professional as a key point of contact is important to people - but not only to discuss clinical or medical issues, but as a dedicated support for people's wider holistic and emotional needs as well as a source of advice and signposting to other sources of trusted information.

Some of the things that matter most to people are assuring support for their family members who are also impacted upon by their cancer diagnosis. Remaining in work is important to people in employment. People with caring responsibilities do not want to worry the people they care for, but they need reassurance and support around continuity of care for the people they care for, should they ever be unable to provide care due to their own ill-health or treatment.

Whilst people are understanding that COVID-19 has impacted on their care – the thing that matters most to people is assuring the continued involvement of their families in clinical and other discussions – as both a source of support for the person diagnosed with cancer, but also as a means of assuring family members feel involved in decisions that impact upon them.



6. Limitations

Despite promotional efforts, it is acknowledged that the sample of people who opted in to participate is limited – reflecting the views predominantly of working-aged females residing in or around the central belt of Scotland. Further consideration on how to widen engagement and involvement of a more diverse range of people, including those with protected characteristics, would be welcomed. Additional targeted engagement with the following under-represented groups within the four focus groups held to date could add a different perspective:

- **People who identify as male**
- **Remote rural and island communities**
- **Ethnic minority communities**
- **Young people**
- **Older people**
- **People diagnosed with rarer/less survivable cancers**
- **People with lived experience of accessing cancer prehabilitation services and/or nutritional, physical or psychological support.**



7. Recommendations

As the above findings highlight, there are key elements of people's lived experience of cancer services that can help inform the design and development of cancer prehabilitation services and tools. The ALLIANCE recommends:

- 1. Continue to engage with people affected by cancer to assure any resultant cancer prehabilitation service proposals meet the needs of current or future cancer prehabilitation service users and their families or supporters. This should include targeted engagement with the under-represented voices identified in section six to identify potentially different perspectives.**
- 2. Ensure people affected by cancer have access to flexible, person centred nutritional, physical and psychological support before, during and after cancer treatment as part of a continuum of care based on individual need.**
- 3. Develop careful messaging through social marketing and other health communication methods to promote the benefits of psychological, physical and nutritional interventions. Messaging and communications must take account of individual preferences for language and terminology; different levels of understanding and health literacy; and potential sensitivities regarding physical or psychological health experienced by people newly diagnosed with cancer.**
- 4. Design cancer support services, including prehabilitation, that reflect the standards and quality of care expected by people affected by cancer, including, but not limited to an expressed desire for:**
 - a timeous offer of prehabilitation support immediately following diagnosis;
 - personalised, local and flexible prehabilitation service provision that includes options for digital service provision and face-to-face services that create opportunity for personal connections;
 - out of hours access to support from a professional involved in their care throughout prehabilitation and beyond;
 - telephone helplines or single points of contact to be staffed;
 - greater ease of access to care plans and results of assessments and/or tests for both the patient and all clinicians involved in their care;
 - the burden of completing assessments and questionnaires to be kept to a minimum;
 - improved signposting and access to trusted sources of information online for people affected by any cancer, including rare and less survivable cancers;

- greater involvement of family members or supporters in clinical discussions if the person affected by cancer wishes them to be.
5. Disseminate the findings of this report widely, alongside other available sources of information on people's lived experience of cancer services, to ensure that cancer prehabilitation service design decisions are influenced by what people affected by cancer have told us matters most to them.



8. Acknowledgements

Heartfelt thanks to all people affected by cancer who contributed to this report.

The ALLIANCE has welcomed the opportunity to work in partnership with Scottish Government to engage with people affected by cancer to explore the views and perceptions of cancer prehabilitation. Special thanks to Debbie Provan, Clinical Advisor, Cancer Policy Unit, Scottish Government for all her advice, facilitation and support throughout the whole engagement process.

If you have any questions about this report, or anything else you would like to discuss with us, please get in touch at macmillan@alliance-scotland.org.uk

We would love to hear from you.

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. As of July 2021 we have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

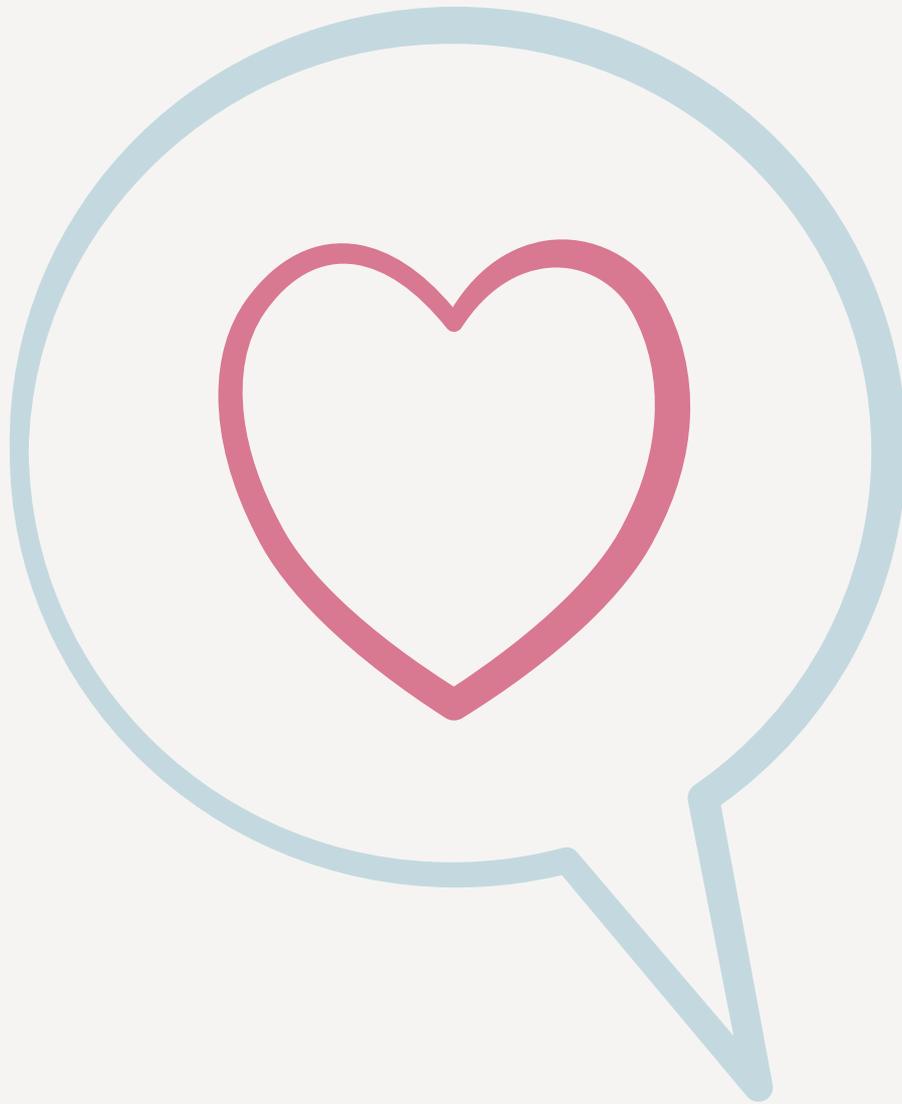
Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has **three core aims**; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.



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The ALLIANCE is supported by a grant from the Scottish Government. The ALLIANCE is a company registered by guarantee. Registered in Scotland No.307731. Charity number SC037475. VAT No. 397 6230 60.

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