

## **Cancer prehabilitation focus groups insights report: response and action**

In late 2021, the Cancer Prehabilitation Implementation Steering Group (CPISG)\*, which was commissioned by the Scottish Government, asked The Health and Social Care Alliance to lead a series of focus groups with people affected by cancer. The purpose of the focus groups was to discuss the principles of cancer prehabilitation and to understand if, and how, it could support people affected by cancer to achieve better outcomes and/or improve experience. The initial findings from the focus group were shared with the CPISG in January and March 2022, with the published version made available online in April 2022. The report set out five recommendations and the following paper sets out how the CPISG are already responding to these recommendations. It is expected that in time, the response of the CPISG and its members will develop further. We will also continue to gather and use more feedback and will work hard to ensure as many groups as possible are heard.

The full report outlining the findings of the focus groups can be accessed via the [Alliance website](#).

\*The CPISG includes representatives working in Scottish Government, NHSScotland, Regional Cancer Networks, academia/research, and cancer charities.

### **Acknowledgements**

The CPISG would like to extend their thanks to everyone who participated in the focus groups. You generously shared your time and experience and we understand how important it is that we listen to and consider these experiences.

Thanks are also extended to the Alliance for advertising, organising, facilitating, analysing and reporting on the focus groups. Thank you.

### **Recommendations and our response**

#### **1. Continued engagement**

You Said: 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 6 to identify potentially different perspectives.

We Did/Will Do: We welcome this suggestion and strive to ensure people affected by cancer have the opportunity to drive and inform our work. We already use insights gathered from a range of sources (i.e. [charities](#) working directly with people affected by cancer and [Care Opinion](#)) to inform our wider Cancer Policy decisions. We will continue to embed these tools as we move forward and will also look to utilise them as effectively as possible within any prehabilitation/rehabilitation developments.

The prehabilitation website which is under development will also seek feedback from users through two specific directives:

1. Those who wish to share their experience of care received will be signposted to Care Opinion. This will allow the story to be viewed by members of the public, those involved in the individual's care, and those working in NHSScotland and Scottish Government.
2. Those who wish to comment on the content of the website, suggesting areas for improvement or what they liked, will be able to do so via an email and/or contact form located on the website.

Through funding awarded by the Scottish Government, Maggie's have introduced [prehabilitation workshops](#) to each of their eight Scottish Centres. The impact of this is being evaluated through questionnaires, and those who give permission to be contacted at a later date may be invited to participate in an interview or focus group. It is expected that this exercise will allow us to better understand the impact of prehabilitation more generally as well as understanding the Maggie's prehabilitation impact. The Scottish Government and Maggie's team will strive to ensure that feedback is representative of those using the service. Should it appear as though some typically under-represented groups are not reached through the Maggie's offer, every effort will be made to rectify this.

Work to understand the views and experiences of people affected by cancer is also taking place at a Regional level. For example, [North Cancer Alliance](#) (NCA) are developing a partnership of third sector organisations to support us to understand the needs of different patient groups. Their prehabilitation project also has a lived experience group to advise and sense check ideas and pathway developments.

## **2. Flexible, Person Centred Care**

You Said: 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.

We Did/Will Do: This is a core aim of our prehabilitation work. We are working with service providers to provide the tools they need to deliver the best possible services to all who would benefit from them at each point in the cancer pathway i.e. before, during and after treatment and for those not undergoing treatment.

The CPISG and its members oversee the development of a prehabilitation website which is designed to support people affected by cancer to access first-line, person centred nutritional, physical and psychological information. The website will also point people towards services that are available in their local area which could help with more complex care needs.

The Regional Cancer Networks and their respective NHS Health Boards, and the [Scottish Cancer Coalition](#) and [Less Survivable Cancers Taskforce](#) are also working independently and collectively to meet this recommendation. For example, amongst other activities, NCA are actively working with Health Boards to deliver projects focused on prehabilitation and they are also looking at how they can best communicate relevant information to patients. The [West of Scotland Cancer Network](#) (WoSCAN) are also working with services across its four Health Boards to identify

and address gaps in prehab service provision, whilst raising awareness of existing services.

Given feedback from the focus groups about the importance of language and ongoing help and support, both the CPISG and its partners will ensure these points are continually considered and addressed as we move forward. We generally refer the ongoing support from the point of prehabilitation as the rehabilitation continuum and do continue to advocate for this however, it is recognised that there is a focus on prehabilitation at the moment and that cannot be to the detriment of wider needs.

### **3. Messaging**

You Said: 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.

We Did/Will Do: We have heard a range of views regarding how we should develop and deliver messages, and this is something we will give continued consideration to. We have opted to continue to use the term 'prehabilitation' as it has meaning in the clinical community and there is a lot of reference to it in public messaging which we have no control over. However, when we do use 'prehabilitation', we will look to explain it in accessible terms and will continue to take feedback on our descriptors.

Our website will use written and audio-visual (video) messages. Our videos will have subtitles enabled and we are working to accessibility guidelines. Care Opinion can be accessed via telephone, post and a website. The Care Opinion website also has a number of embedded features that support those with additional needs to share their story and to interact with the website itself.

Maggie's have developed a communications plan to highlight their prehabilitation offer, and again, they are utilising a number of platforms and audio-visual tools to ensure the message is heard and understood. The evaluation of their prehabilitation service should also provide further information about how we can best support diverse groups affected by cancer including supporters of those with cancer.

### **4. Service Design**

You Said: 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.

We Did/Will Do: We welcome each of these suggestions and will ensure that where they go beyond prehabilitation, relevant teams and services are aware of the recommendations.

Our newly developed prehabilitation website aims to support access to first-line information and highlight services that are available in local communities. In the first instance the website will include a list of charities (members of the [Scottish Cancer Coalition](#)) and what each can offer ([More Support](#) page). In the future it will also include links to [Scotland's Service Directory](#), further improving awareness of wider services available in local communities.

The prehabilitation offer being tested by Maggie's is open to the supporters of people diagnosed with cancer as is the evaluation. We have always recognised the importance of supporting all those affected by a diagnosis. However, feedback from the focus groups has emphasised the importance of this, and as a result we will give greater attention to this going forward.

Leads within NCA and WoSCAN are working with their respective Boards to implement all of the work being delivered Nationally. They are also identifying and utilising local services that can be used to support the delivery of prehabilitation, and they are making use of local data to ensure interventions are timely and effective.

## 5. Reporting

You Said: 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.

We Did/Will Do: The findings contained within the report have been shared with the CPISG in the first instance. That group has representatives from the Scottish Government, NHSScotland, regional cancer networks, higher education, and cancer charities. It is expected that each group member will share the report with their networks as appropriate.

We will also share the published report via our prehabilitation website and will consider any other mechanisms available to us that will maximise reach. This should ensure the views and experiences of those who contributed are heard and considered across Scotland and beyond.