

# Co-designing a nutritional prehabilitation solution for head and neck cancer patients receiving radiotherapy: A novel participatory approach

Linda A Cantwell

`linda.cantwell@liverpool.ac.uk`

University of Liverpool

Joanne M. Patterson

University of Liverpool

Grahame Smith

Liverpool John Moores University

Mary Gemma Cherry

University of Liverpool

Nefyn Williams

University of Liverpool

Alison Bryant

Co-ENHANCE PPIE Steering Group

Greg Hunt

Co-ENHANCE PPIE Steering Group

Carol Hunt

Co-ENHANCE PPIE Steering Group

Saiqa Ahmed

Co-ENHANCE PPIE Steering Group

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## Research Article

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# Abstract

## Background

Head and neck cancer (HNC) is a global health burden associated with socioeconomic health inequalities. On diagnosis, HNC patients experience high rates of malnutrition. Radiotherapy treatment side effects further exacerbate malnutrition by causing eating and drinking difficulties. Malnutrition is associated with poor treatment tolerance and decline in quality of life. Prehabilitation involves targeted interventions delivered before oncology treatment to optimise physical wellbeing, nutrition, treatment readiness, treatment tolerance and improve recovery. However, there is a lack of robust evidence demonstrating the implementation and approaches used in nutrition prehabilitation interventions in HNC. This study aims to co-create innovative solutions/features for a nutrition prehabilitation intervention for patients undergoing radiotherapy for HNC.

## Methods

Ten participants with lived experience and eleven professionals working in the field were recruited to this co-design study. We used a Living Labs approach that placed end users (people with lived experience) at the centre of innovation design and development. A series of in-person and online workshops and working groups created a space to explore the barriers and enablers for nutritional prehabilitation and informed an iterative process of solution ideation and design.

## Results

We identified five key action themes representing the barriers and enablers to prehabilitation; Information- accessibility and amount, Emotional and Mental Wellbeing- demands and impact, Nutritional and Physical Wellbeing- demands and impact, Social Connections- creating support and acceptance and The Care Pathway. We agreed and co-created three solutions to be delivered within a HNC nutritional prehabilitation intervention. These include; a three key actions point card, a nutrition prehabilitation passport, and education of the personal importance of nutrition and physical strength to support behaviour change.

## Conclusion

Using a novel participatory approach has empowered those with experience of the problem to collaboratively co-create acceptable solutions for use within the real-world context. Future feasibility testing will determine the acceptability, accessibility and implementation of these co-designed prototypes as part of a nutrition prehabilitation intervention for HNC radiotherapy patients in an NHS setting and will inform any adaptations required before larger-scale evaluation.

## Trial Registration:

ISRCTN12090713 (Registered 21 Sept 2026)

## Plain English summary

People with head and neck cancer (HNC) can lose a lot of weight and muscle (undernourished). This can happen on diagnosis, before treatment starts. Radiotherapy can cause taste changes and make it painful to chew and swallow, which can make undernutrition worse. Being undernourished can make treatments such as radiotherapy more difficult to tolerate. Nutrition prehabilitation supports people to improve their nutrition before treatments such as radiotherapy start. This helps people become better nourished and stronger. It can help people to get through treatment and improve their chance of recovery and getting back to activities that matter most sooner. It is important to work with people with lived experience of HNC to create meaningful solutions that are practical and acceptable in real-world settings. This study involved patients, caregivers, and professionals working together with researchers to understand what makes it harder or easier for patients (and caregivers) to take part in nutrition prehabilitation before HNC radiotherapy treatment. The main areas they shared were about lack of information, not understanding nutrition and knowing more about being strong, mental health, having family or peer support, and the complex care pathway. With a better understanding of the challenges, the group worked together to agree on possible ideas and solutions that would make nutrition prehabilitation easier for patients to access, understand and follow. Three example solutions were created together; a three actions point card, a nutrition prehabilitation passport and making the prehabilitation patient centred to help people understand the benefits of nutrition.

## Background

Head and neck cancer (HNC) is the 7th most common cancer in the UK and worldwide (1, 2). Treatment involves aggressive multimodal therapies including surgery and/or radical radiotherapy with or without chemotherapy. HNCs include those occurring in the mouth, tongue, throat, nasal cavity, salivary glands and sinuses. Both the physical location and treatments targeted at these vital structures can result in eating and drinking difficulties. Consequently, it is a life altering diagnosis that has a significant negative nutritional, physical, and mental impact on patients (3).

Globally a diagnosis of HNC is associated with a range of geographical, socioeconomic, gender and age-related inequalities (4). In England, despite access to free health care, incidence rates are twice as high in areas of greatest socioeconomic deprivation compared to the least (5). In addition, nearly 60% of patients in more deprived areas are diagnosed with advanced stage HNC (5). In the UK, treatment for HNC is centralised within large specialist centres, expanding the travel distances required by patients to receive treatment (6). This increases the emotional, physical and financial burden of cancer treatment (7).

Malnutrition rates in HNC before and following radiotherapy treatment reach up to 70% (8, 9). Radiotherapy increases metabolic demands and causes both acute and long-term symptoms such as mouth ulcers, pain, thick phlegm, dry mouth and swallowing difficulties which further compromises nutritional intake leading to significant weight and muscle loss (10–12). Malnutrition before treatment is a risk factor for negative outcomes including, poor treatment tolerance, reduced Quality of Life (QoL), mortality (3, 13) and greater healthcare costs (14, 15). Given the high prevalence of malnutrition and associated negative patient related outcomes and economic impact, the HNC population has the potential to gain from early patient-centred nutrition focused interventions before treatment begins. This approach is supported by patient and caregiver experience feedback (16, 17).

Prehabilitation could provide the opportunity to deliver an early nutrition-focused intervention to HNC patients to treat any malnutrition and improve nutrition reserves before treatment. Cancer prehabilitation is *“a needs-based multi modal intervention before and during cancer treatment to optimise physical, nutrition and readiness for and tolerance of treatment and improve recovery”* (18). The three key pillars of prehabilitation include physical activity, nutrition and emotional wellbeing. Several systematic reviews have demonstrated the effectiveness of multi-modal prehabilitation interventions in cancer, with some highlighting nutrition prehabilitation alone can confer clinical and patient benefits (19–21). UK HNC guidance recommends that HNC patients should have access to nutritional prehabilitation (22) however there is a lack of robust published data regarding the content, acceptability and implementation of nutritional prehabilitation interventions in HNC pathways, especially before radiotherapy (23).

Those with lived experience of conditions and associated challenges should be at the centre of innovation development. The complexity of HNC care, treatment, and symptom burden reinforces the importance of co-designing innovations and solutions based on the lived experience of patients and caregivers with professionals. Existing co-design research has been used to improve nutrition information and support for HNC patients and caregivers, (24) and create meaningful interventions addressing the challenges faced by those living with incurable HNC (25, 26). These collaborative approaches ensure that solutions are acceptable and accessible for real life application to meet the complex needs of patients. Living Labs are an example of a participatory action research approach (27), and have a growing number of applications within the healthcare innovation environment. Defined by the European Network of Living Labs (EnoLL) as *“user-centred, open innovation ecosystems based on a systematic user co-creation approach, integrating research and innovation processes in real-life communities and settings”* (28). Living Labs provide a model for facilitating innovation according to these defining principles which could be beneficial for navigating the complexities associated with HNC. They are built on a strong engagement and empowerment ethos and can be applied to a range of end users and stakeholders with a focus on developing a solution with real-life benefits.

This study describes the use of a Living Labs approach to facilitate the **co-creation** of solutions/innovations for a nutritional **prehabilitation** intervention for **head and neck cancer** patients receiving radiotherapy (Co-ENHANCE).

The objectives of this study were to

1. Understand the barriers, challenges and enablers experienced by HNC patients, caregivers and health professionals when considering nutrition and preparing for radiotherapy treatment (nutrition prehabilitation)

and then

- 2) Use these findings to facilitate ideation and co-design amongst co-creation participants for solutions/innovations that would be tested and evaluated within a future nutritional prehabilitation intervention feasibility study

## Methods

### Study design

This study reports the intervention development phase for a nutritional prehabilitation intervention for HNC radiotherapy patients grounded in co-production principles to address the core elements in complex intervention development. This is the first of the four phases of MRC complex intervention development framework, preceding feasibility (which will be reported as part of a later study), evaluation and implementation (29) .

Our Living Lab was a collaborative space co-ordinated by the lead researcher at a university in the northwest of England delivering a series of in-person and online workshops, working groups and openly inviting further feedback through email.

This study followed a Living Labs Integrative Process (LLIP) for innovation/solution development to create a space to meet the study objectives (30). This iterative process involves three spaces, problem space (understanding the problem including barriers and enablers), solution space (involving ideation, prototype development and prototype testing), followed by deployment space (large scale implementation) (Fig. 1). This iterative approach gradually explores, improves, and refines the innovative solutions through the successive stages where the results or outputs are not predetermined. How we followed the LLIP in our study is shown in Fig. 2.

### Procedure

The lead researcher (LC) managed all workshops and working groups. All co-creation participants were seen as equal partners in the co-creation process. At the start of each workshop the lead researcher outlined a set of ground rules which focused on respect, confidently and equal opportunities and participants agreed to them. Semi structured topic guides developed with the research team and patient and public involvement and engagement (PPIE) steering group guided the workshops (Fig. 2). Clinicians with experience in the Living Labs process or HNC (GS, AS, LJW) and a Patient and Public Involvement and Engagement (PPIE) advisory group facilitated in-person and online workshops. Facilitators supported group discussions and took notes which formed the

data set for analysis. In-person workshop participants also used sticky notes and flip charts to share their thoughts and views, and the research team added these materials to the data set. For online workshops the audio recording transcriptions and information written in the online chat created a data set.

The lead researcher audio recorded all in person workshop to support immersion in the data, ensure that the notes reflected the conversations and to obtain accurate quotations to illustrate the identified action themes and outputs generated from the data set.

All experiences shared by participants were acknowledged as important to developing a deeper understanding of the context and influencing factors surrounding nutrition and prehabilitation. The lead researcher regularly acknowledged participants' contributions while respectfully clarifying the scope of the study. This included explaining that individual concerns, or concerns unrelated to nutrition and prehabilitation before radiotherapy, could not be addressed within the study aims and objectives outlined in the protocol.

Demographic data of recruited patients and caregivers, including sex, age, education, employment, first part of postcode, HNC diagnosis site, treatment and time since completion of primary treatment was collected through a written questionnaire. Professional background of recruited health professionals and stakeholders was collected during the workshop verbal introductions.

A PPIE steering group guided and supported the design and delivery of this study, ensuring that the research remained acceptable, accessible and relevant to potential recruited participants. The steering group comprised four patient and public advisors who were identified through a directory of Trust public, patient and caregiver representatives with experience of head and neck cancer or cancer. The steering group developed a study mission statement and provided strategic oversight throughout the project.

*Improving your chances to feel better and stronger before, during and at the end of your radiotherapy treatment*

## Participants

We purposefully sampled two NHS sites in the northwest of England as patient identification centres to identify HNC patient participants that may be harder to reach and to get diverse experiences. The northwest includes boroughs that experience the highest levels of socioeconomic deprivation. Study adverts were also disseminated across local and national HNC support groups, a local cancer alliance, Co-ENHANCE social media account, regional dietetic and speech therapy groups and professional specialist dietetic groups.

Study eligibility included HNC patients who had completed treatment for HNC, caregivers of HNC patients, health care professionals (i.e. allied health professionals, nurses, medical consultants/trainees) working in HNC or prehabilitation, stakeholders'/decisions makers involved with HNC or prehabilitation (i.e. cancer alliance, clinical quality groups). All eligible participants had to be living or working within the UK.

The study recruited 21 co-creation participants; seven patients, three caregivers, and eleven health professionals or stakeholders with experience in HNC or prehabilitation. Two of the caregivers attended with their partners and one attended independently. Patient and caregiver characteristics are outlined in Table 1. Of the professionals, these included dietitians (n = 7), clinical nurse specialist (n = 1), speech and language therapist (n = 1), consultant oncologist (n = 1) and a member of a cancer alliance (n = 1). Seven worked in HNC services and four worked in, or with the development of, prehabilitation services. Collectively, patients and caregivers are referred to as those with lived experience and health professionals and stakeholders as professionals.

The study began by engaging exclusively with lived experience participants in two workshops, positioning them at the centre of problem-solving and innovation development. All participants were part of the initial workshops, the smaller co-design phase working groups involved around five to six co-creation participants per group to co-design/create each of the proposed prototype solutions.

The lead researcher invited wider review and consensus from all co-creation participants, the research supervisory team and PPIE steering group through final in-person and online workshops, meetings or email correspondence (Fig. 2).

## Data analysis

The lead researcher (LC) used rapid thematic analysis (31) to sequentially analyse each data set after the problem phase workshops. They used Excel to develop initial codes and generate proposed themes representing the barriers and enablers for nutritional prehabilitation. These were considered action themes. The lead researcher shared the proposed action themes with all co-creation participants and facilitators for review, correction and agreement. The action themes were also reviewed and refined by the PPIE steering group and research supervisory team discussions. This data iteratively informed the intervention/solution development according to the LLIP (Fig. 1& 2).

Table 1  
Lived experience participants demographics

| Characteristics                                                                                                                                                                                                                | No.   |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------|
| Patient                                                                                                                                                                                                                        | 7     |
| Caregiver                                                                                                                                                                                                                      | 3     |
| Sex                                                                                                                                                                                                                            | 7     |
| Male                                                                                                                                                                                                                           | 3     |
| Female                                                                                                                                                                                                                         |       |
| Age range (years)                                                                                                                                                                                                              | 59–84 |
| Highest level of Education/Qualification                                                                                                                                                                                       | 1     |
| No qualifications                                                                                                                                                                                                              | 2     |
| Level one (1–4 GCSE)                                                                                                                                                                                                           | 0     |
| Level two (> 4 GCSE)                                                                                                                                                                                                           | 0     |
| Level three- upper secondary qualification or advanced further education                                                                                                                                                       | 4     |
| Level four & higher (Degree, NVQ or similar)                                                                                                                                                                                   | 2     |
| Apprenticeship                                                                                                                                                                                                                 | 1     |
| Other- professional                                                                                                                                                                                                            |       |
| Employment *                                                                                                                                                                                                                   | 2     |
| Working                                                                                                                                                                                                                        | 8     |
| Retired                                                                                                                                                                                                                        | 3     |
| Voluntary work                                                                                                                                                                                                                 |       |
| Primary head and neck cancer site #                                                                                                                                                                                            | 2     |
| Oral cavity                                                                                                                                                                                                                    | 3     |
| Oropharynx                                                                                                                                                                                                                     | 1     |
| Hypopharynx                                                                                                                                                                                                                    | 1     |
| Prefer not to say                                                                                                                                                                                                              |       |
| Treatment                                                                                                                                                                                                                      | 6     |
| Surgery and Radiotherapy +/- Chemotherapy                                                                                                                                                                                      | 1     |
| Radiotherapy + chemotherapy                                                                                                                                                                                                    |       |
| Time since completed treatment                                                                                                                                                                                                 | 1     |
| 6–12 months                                                                                                                                                                                                                    | 1     |
| 1–3 years                                                                                                                                                                                                                      | 1     |
| 3-5 years                                                                                                                                                                                                                      | 4     |
| > 5 years                                                                                                                                                                                                                      |       |
| Caregivers' relationship                                                                                                                                                                                                       | 3     |
| Spouse (married, civil partnership)                                                                                                                                                                                            |       |
| Time when partner completed treatment                                                                                                                                                                                          | 3     |
| > 5 years ago                                                                                                                                                                                                                  |       |
| Note. N = 10. Some categories are not mutually exclusive; therefore, totals may exceed N. *Employment status reflect multiple responses where applicable. # Primary cancer site and treatment variables apply to patients only |       |

## Results

### Problem Space- understanding the problem

None of the lived experience participants had experience of being offered nutritional prehabilitation before radiotherapy. Despite this, there was unanimous agreement across all the workshops that nutritional prehabilitation would be important for future HNC patients before radiotherapy treatment.

Analysis of the problem-space workshop data generated five key action themes representing barriers and enablers to nutritional prehabilitation: information- accessibility and amount; emotional and mental wellbeing- demands and impacts; nutritional and physical wellbeing- demands and impacts; social connections- creating support and acceptance; and the care pathway. Across these themes, 12 subthemes were identified from the lived experience workshops and nine from the professional workshops (Fig. 3). Here we have summarised the findings by key themes with Tables 2 and 3 providing quotations to further illustrate the subthemes.

Table 2  
Quotation to illustrate patient and caregiver (lived experience) action themes and subthemes

| Theme                                                                | Quotation                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
|----------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Theme 1. Information – Accessibility and Amount</b>               |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| 1.1 Lack of information<br>(-)                                       | <p><i>"I feel like I should have been told about diet before treatment and there was no mention of this"</i></p> <p><i>"But didn't know why I had to see nutritionist."</i></p> <p><i>"You need to build yourself, with high protein drinks and things before treatment. But I didn't know anything."</i></p> <p><i>"They never turn around and said you might get depressed here, you might be fed up, you are going to go through a hard time, no no no you are going to have 30 radiation or you you'll die, they didn't say you are going to lose weight, they didn't tell me I might go mental in me head or owt like that, nothing."</i></p> <p><i>"Sadley it's a massive lack of information and sometimes when you get the information it's too late. Like when you've lost two stone in weight. Before that no one told me that I would lose weight".</i></p> <p><i>"I think that's what they concentrate on telling you about the diagnosis telling you will have radiotherapy, how about something like this, they've got to tell you, you probably won't eat, you will struggle eating, I'm sure, I would have asked what does this mean?"</i></p>                                                                                                                                                                                                                                                                                                                                                                                                                           |
| 1.2 Key information (+)                                              | <p><i>"Important to know about feeding tubes and to be given the option to have a feeding tube."</i></p> <p><i>"What is the nutritional, how do you know what you should be eating, for the best nutrition"</i></p> <p><i>"The greatest source of information I found... Macmillan books... There is a book this thick and it's about this, and it helps you mentally"</i></p> <p><i>"If you had information taken down to take with you..then I can read it again and then next day and the next day."</i></p> <p><i>"Some sort of leaflet or pamphlet with information like protein all the things you've got to get like your protein and carbs and what calories and what should be on food now I think."</i></p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| 1.3 Information uncertainty (+/-)                                    | <p><i>"Having someone there to take information. i.e. caregiver."</i></p> <p><i>"The main things that you come across is information overload.. It's prioritising a lot of information, in order, that's the key."</i></p> <p><i>"The thing is you can't say to people if you told people what was going to happen, they wouldn't go through with it for sure."</i></p> <p><i>"Sometimes I think too much information, I mean [partner with HNC] didn't know what was going to happen, I knew exactly where we were going and we were in trouble, like a steam train, he didn't want to know, so where do you draw the line, so you enable without disabling. Getting it in the right time in the right place and to the right level yes."</i></p> <p><i>"What I think for a lay member, for a patient it's really important, to educate people about this about prehabilitation, because imagine somebody might not be familiar with this. It might be that they are new to this country, maybe it's about cultural and knowing people's culture and background is really important maybe they're coming from a BME community or a South Asian community and where cancer stigmatises people and people might not feel comfortable we need to educate people, we need to give them information leaflets we need to give them word of mouth and coming from a trustworthy person, maybe coming from a GP, coming from a community centre coming from a champion, who they can trust, nutrition and make a plan for them this is nutritionally good for you and this is the plan"</i></p> |
| <b>Theme 2. Emotional and Mental Wellbeing- Demands and Impacts</b>  |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| 2.1 Control (+/-)                                                    | <p><i>"A lot of this is coming back to the mental side. To understand the attitude, personality, you may have mental control, a lot of this is, is about physical, if you don't have mental side of it it's a lot more difficult"</i></p> <p><i>"Biggest problem with nutrition is that when you start treatment you don't want to eat. It's like when you are ill, like when you have the flu, you don't want. That's the biggest problem, not how you should. You don't want to eat. You just feel lousy and you don't want to eat, it's like when you are ill you don't want to eat."</i></p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| 2.2 Motivation (+/-)                                                 | <p><i>"If you're told you are going to have major operation and after that you're going to have 6 weeks of Radiotherapy and you're going to feel crap running and you're not going to want to eat and won't be able to eat but you need to have strength. So that is why you should be engaged with this."</i></p> <p><i>"I think for me it was losing all, I had a lot of muscle, losing all that, I did get back to playing rugby, but it's psychological and then having no saliva, there's few hurdles and no one realises, I'm not saying no one helped me, you had to just get on with it."</i></p> <p><i>"I went through a phase when I gave up, I was massively depressed."</i></p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| 2.3 Psychological impact (-)                                         | <p><i>"Wearing a mask caused anxiety."</i></p> <p><i>"I think a lot of it is a lot about attitude. if you've got a positive attitude I was lucky that mine could have been a lot worse they could have had my tongue cut off there is always something worse that can happen to you, so a lot of it is psychological and some people are not like that some people, are my brother is like doom and gloom, were as I am not like that, it doesn't matter what happens to me I just get up and think..."</i></p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Theme 3. Nutritional and Physical Health- Demands and Impacts</b> |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| 3.1 Being strong (+)                                                 | <p><i>"You need to have strength. You might have some now but once you go through that you are going to have a minimum, bare minimum, of energy for two months, and that's going to be made even longer, when you are going to lose muscle and you are going to lose strength."</i></p> <p><i>"But it's not just about gaining weight, it's about muscle for the strength"</i></p> <p><i>That wasn't good, there was nothing of me, I disappeared. All my muscle tissues in my arms, where gone, what happened to my arms I've no idea."</i></p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |

| Theme                                                               | Quotation                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|---------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Theme 1. Information – Accessibility and Amount</b>              |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
|                                                                     | <i>I was physically fit beforehand, so I would say a big precursor to having an operation is get yourself fit. I'm not saying to an Olympic standard but just do some exercise. It helped me through both."</i>                                                                                                                                                                                                                                                                                                                                                           |
|                                                                     | <i>"But you have to be as strong as you can before you start because that determines the outcome for you I think"</i>                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|                                                                     | <i>"I used to try press up, after my op, but I had blood in my mouth, so I thought I can't do that now there was a mouthful of blood, so I thought I can't do that any longer."</i>                                                                                                                                                                                                                                                                                                                                                                                       |
| 3.2 Managing side effects (-)                                       | <i>I think for me it was losing all, I had a lot of muscle, losing all that, i did get back to playing rugby, but it's psychological and then having no saliva, there's few hurdles and no one realises, I'm not saying no one helped me, you had to just get on with it</i>                                                                                                                                                                                                                                                                                              |
| <b>Theme 4. Social Connections -Creating Support and Acceptance</b> |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| 4.1 Peer support and connecting with others (+)                     | <i>"When being prepared asking demographic questions- finding out who is your support network and then find out who it is you need."</i>                                                                                                                                                                                                                                                                                                                                                                                                                                  |
|                                                                     | <i>"I had a big support network, but I've always lived on my own since then, so both times now it's about picking myself up"</i>                                                                                                                                                                                                                                                                                                                                                                                                                                          |
|                                                                     | <i>"Somebody needs to be supporting the patient journey."</i>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
|                                                                     | <i>"The wife has helped me and the stepdaughter has helped. [ with nutrition]"</i>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| 4.2 Family and caregiver support (+)                                | <i>"There was an impact on husband- he has to eat at that time"</i>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|                                                                     | <i>"Caregivers are as important"</i>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
|                                                                     | <i>"I had researched it all I was armed and ready, but it was hard, I could tell him I knew you had to eat it..... As a partnership, he's an ex-miner he's very strong, well I look into things and I research the dietitian and nutrition."</i>                                                                                                                                                                                                                                                                                                                          |
|                                                                     | <i>"I think you need another half, someone with that person whether that is a wife or spouse, that other persons needs to be informed equally, because they are the one when it goes into treatment and before that are getting on with it and doing."</i>                                                                                                                                                                                                                                                                                                                |
|                                                                     | <i>"I know that my husband wouldn't have been able to do it all, the eating that he needed, on his own."</i>                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
|                                                                     | <i>I was that practical getting on with it, emotionally crumbling, and he was just a strong ex miner who just couldn't believe what had happened and in denial."</i>                                                                                                                                                                                                                                                                                                                                                                                                      |
|                                                                     | <i>"Tube feeding meant change to work and social activities"</i>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
|                                                                     | <i>"You have to learn to eat. You have to learn how to do it again. I remember that Christmas, having stacks of gravy and a little mash and it was case of do what you can. That was the start of my learning to eat."</i>                                                                                                                                                                                                                                                                                                                                                |
| 4.3 Personal adjustments (+/-)                                      | <i>"You just want to be normal don't you?"</i>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
|                                                                     | <i>"And it won't be the same normal will it, but It's a new normal that we embrace if we can."</i>                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
|                                                                     | <i>We like to go out to eat. But we couldn't go because it affected [partner with HNC] because as he couldn't eat</i>                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|                                                                     | <i>"People need to get their heads around the fact that you have to make lifestyle changes. I think that's a good one beforehand. I think people do need to realise that it's a lifestyle, it's like a diet, not to lose weight, and you've got to get your head around this, and if that's the worst that can happen to you, that you have to change your diet then it's not that bad."</i>                                                                                                                                                                              |
|                                                                     | <i>"People need to get their heads around the fact that you have to make lifestyle changes. I think that's a good one beforehand. I think people do need to realise that it's a lifestyle, it's like a diet, not to lose weight, and you've got to get your head around this, and if that's the worst that can happen to you, that you have to change your diet then it's not that bad."</i>                                                                                                                                                                              |
| <b>Theme 5. The Care Pathway</b>                                    |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| Disconnected pathway (-)                                            | <i>"But all the information is there and the books are fantastic, great source of information, it learned me a lot, they have all the information there you need, you don't need to ask them for it, you just get the books and take them home, you learn so much, I learnt too late mostly, but it's all there".</i>                                                                                                                                                                                                                                                     |
|                                                                     | <i>"I think at time of diagnosis it [nutrition] should be discussed"</i>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
|                                                                     | <i>"And I don't think it's just about getting the information, I think it's about where it's put because when you're diagnosed, there's a lot of information you're having the mask fitted where does that fit in with where the right time to put it in is and where is the importance, we're here for this appointment, were having this done were the at the dentists we're getting teeth out, were doing this, we need it there, in the right order, it needs to be put in early on, when all the information is there, it needs to be there in the right order."</i> |
|                                                                     | <i>"And also, I don't think nutrition is taken seriously, well, it's not at the forefront of the NHS, and it should be, it should be given more importance, because if not you're just going to have people going back, so I think there is definitely a gap for where, but I'm not sure, I think if you went to see the oncologists they are more likely just to tell you about your treatment and not bothering about your diet."</i>                                                                                                                                   |
|                                                                     | <i>"Oncologist isn't the nutrition expert, I just think, I've been to see [ a dietitian] in [place name] and that was brilliant for me and I can ask her a question,....., it was brilliant meeting [the dietitian] and just opened up, she was able to guide me, on what I need to do.."</i>                                                                                                                                                                                                                                                                             |
|                                                                     | <i>"I was a bit, rabbit in the headlight it all happened so fast."</i>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |

Table 3  
Quotations to illustrate professionals' action themes and subthemes

| Theme                                                                      | Quotation                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
|----------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Theme 1. Information – Accessibility and amount</b>                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| 1.4 Information overload (-)                                               | <p>"Sessions can be so overwhelming, and a lot is said and kind of expecting patients to remember that is sometimes a barrier" [04PP]</p> <p>"We did have a clinic for our lung patients, which involved myself [dietitian]f, the physio and Macmillan information and support, and it was quite a heavy day for patients because it took quite a long time to get through all of us and by the end they were just bombarded with information. It was a bit much." [06PP]</p> <p>"It's a lot of information for them to glean in one sitting, in one clinic setting, so we do have to try and stage it as such" [01PP]</p> <p>"They might get some information, but then by the time they've left the room, they've forgotten about it or felt that it was too overwhelming" [04PP]</p> <p>"Having the information there for you to take it in at your own pace when you are ready feels important." [PPIE1]</p>                                                                                                                                                                 |
| 1.5 Available evidence (+/-)                                               | <p>"We haven't published anything yet, our report [prehab service]." [06PP]</p> <p>"So, it's been a case of getting pathways established, getting some data to prove that it's well received and that it works for patients".</p> <p>"Just we need more data like we've talked about and be able to kind of document what we're doing and how we can change patients' pathways as a result of it". [08PP]</p> <p>"Working with local research team to publish findings, specifically focussing on how Prehab can impact RTT [referral to treatment]" [02PP]</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Theme 2 Emotional &amp; Mental Wellbeing- Demands and Impacts</b>       |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| 2.4 Emotional support (+)                                                  | <p>"As a patient the emotional wellbeing is essential to assess and ask about in the patient journey." [PPIE1]</p> <p>"We use EORTC scoring as our wellbeing triage and outcome measure and our OT caseload is mostly emotional wellbeing support versus the typical OT role in an acute hospital setting" [02PP]</p> <p>"Patients do value that written piece of paper because that's how they view that, as hope on a page, when so much else is out of their control and out of their grasp." [01PP]</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Theme 3. Nutritional &amp; Physical Wellbeing - Demands and Impacts</b> |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| 3.3 Making it patient centred (+)                                          | <p>"Key things seem to be like the patients need to really understand how prehab is relevant to them, and going to help them in particular, and not just this sort of general, oh, everyone needs to get fitter and stronger for treatment or surgery" [09PP]</p> <p>"It's the difference between them attending or not some sort of virtual offering does make a real difference." [02 PP]</p> <p>"More sort of individualised understanding of how that, to sort of, that the patient's really got to understand that it's going to benefit them specifically and be able to see how it would be helpful for them." [09PP]</p> <p>"Just having everything in really plain English, trying to avoid jargon so that whether it's a video, whether it is a leaflet patients can understand them really easily." [04PP]</p> <p>"We are providing some virtual clinics and working on electronic resources that we can send out for people and with our bigger funding option, we're hoping to provide satellite clinics, so travelling, a lot closer to patients home". [02PP]</p> |
| <b>Theme 4. Social Connections- Creating Support and Acceptance</b>        |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| 4.4 Social connections (+)                                                 | <p>"Patients sharing experiences who are at the same points of treatment is important" [03PP]</p> <p>"I think I've found that people really like they be able to relate to people in the same situation at the same stage in their journey, I think can be really useful" [09PP]</p> <p>"Without having to sort of formally go to a support group, they're just given that opportunity to be with other people in a similar situation and support each other, which is really beneficial. [ when attending group prehab classes]". [09PP]</p> <p>"Working with four local football clubs and the trusts of associated with those clubs" [11PP]</p>                                                                                                                                                                                                                                                                                                                                                                                                                               |
| <b>Theme 5. The Care Pathway</b>                                           |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| 5.2 Finance (-)                                                            | <p>"[patients can be] Bit fed up of the expense of going over there." [05PP]</p> <p>"They're [patients] trying to save their travel, or their travel money even or, you know, lifts from friends for those appointments which they deem more essential, such as, you know, imaging, oncology appointments etc." [02PP]</p> <p>"We are only temporary funded. So, our funding finishes in...we were initially for two years and then we got an extra five months.. through our charitable trust funds." [06PP]</p> <p>"Improve the offer of prehab across [name of location], but with very limited funding." [11PP]</p> <p>"Provision of dedicated funding" [ 01PP]</p>                                                                                                                                                                                                                                                                                                                                                                                                          |
| 5.3 Continuity of care (+)                                                 | <p>"Just thinking about the continuum of care side of things, I think it's really important for any prehab service or any service that's providing some sort of prehab to think about those MDT links as well. So making sure that if a patient's got a plan set from a multimodal Prehab team or from a clinical specialist.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| pp: professional participant                                               |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |

| Theme                                                  | Quotation                                                                                                                                                                                                                                                                                                                                    |
|--------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Theme 1. Information – Accessibility and amount</b> |                                                                                                                                                                                                                                                                                                                                              |
|                                                        | <i>That plan is readily available on someone's electronic record so that the whole of the MDT can see that, and also they can then be in a position where they can support those changes as well."</i> [02PP]                                                                                                                                |
|                                                        | <i>"Yeah, the whole picture in it, all of the MDT are invested in it as well. So making sure that plan is readily available to support patients to have that continued messaging."</i> [02PP]                                                                                                                                                |
|                                                        | <i>"I do discuss it [prehab nutrition] because I think it's so important."</i> [05PP]                                                                                                                                                                                                                                                        |
|                                                        | <i>"If something was to be on their planning day when they have to go and have the mask and the dental check, etcetera, I think that would work."</i> [05PP]                                                                                                                                                                                 |
| 5.5 Timing & access (-)                                | <i>"Provision isn't always equitable. I think across that sort of pathway, so some MDT clinics don't have access to dietitian and also speech therapy on the day, whereas they do for others."</i> [10PP]                                                                                                                                    |
|                                                        | <i>"Maybe sometimes it's [nutrition assessment] not quite as early as possible."</i> [10PP]                                                                                                                                                                                                                                                  |
|                                                        | <i>"We have a very small window because our clinics are structured on a Monday and a Friday, so it's trying to get that timely prehab intervention in before they actually undergo their surgical procedure or commence their radiotherapy."</i> [07PP]                                                                                      |
|                                                        | <i>"Sometimes due to the demand it can actually be the week before which isn't really that great of an early intervention."</i> [01PP]                                                                                                                                                                                                       |
| 5.6 Centralised services (-)                           | <i>"Think an issue would be that they have to traipse all the way over to [central treatment location]"</i> [05PP]                                                                                                                                                                                                                           |
|                                                        | <i>"The provision of that pretreat is not universal across potentially everywhere."</i> [10PP]                                                                                                                                                                                                                                               |
|                                                        | <i>"We live in a community which has, you know, real issues in terms of coastal and rural communities, and accessing care, and all of our clinics are run in one central place, which can mean a lot of travel for people, which I think for a lot of people does impact their ability to engage and come to subsequent clinics."</i> [02PP] |
|                                                        | <i>"So perhaps that nutrition prehab is starting earlier depending on a bit of a post code lottery and where you're coming."</i> [10PP]                                                                                                                                                                                                      |
| <i>pp: professional participant</i>                    |                                                                                                                                                                                                                                                                                                                                              |

## Action theme one: Information-accessibility and amount

This theme captured the need for earlier, clearer and trusted information about nutrition prehabilitation, while avoiding information overload at an already demanding point in the pathway. Lived experience subthemes included lack of information, key information and information uncertainty; professional subthemes were information overload and available evidence. Lived experience participants described receiving little or no information before radiotherapy about nutrition, physical fitness, or the importance of "building up" before treatment. They valued concise, practical information in verbal, paper-based and online formats that could be revisited after appointments. Professional participants similarly emphasised the importance of consistent messaging across the MDT, while also recognising that limited published evidence and uncertainty about service models and implementation currently restrict long-term funding.

## Action Theme Two: Emotional and Mental wellbeing – demands and impact

This theme describes the subthemes of motivation, control, psychological impact and emotional support. Participants described how diagnosis, anticipated treatment demands and radiotherapy-related side effects could reduce motivation to engage with nutrition and physical preparation. The short period between diagnosis and treatment could also contribute to a perceived loss of control. Nutritional prehabilitation was therefore viewed as a way of offering patients something practical and positive to focus on before radiotherapy. Lived experience participants also highlighted the psychological impact of treatment for both patients and caregivers, reinforcing the need for nutritional prehabilitation to recognise emotional wellbeing as closely linked to patients' capacity to prioritise eating, drinking and maintaining strength. Caregivers often also carried the burden of researching treatment effects and supporting nutritional intake.

## Action Theme Three: Nutritional and Physical wellbeing - demands and impacts

This theme included the subthemes of being strong, managing treatment side effects and making prehabilitation patient centred. Lived experience participants emphasised the importance of being nutritionally and physically optimised before treatment, particularly because they had not anticipated the extent of weight, muscle and strength loss associated with radiotherapy. Some described taking years to regain weight and strength after treatment. Side effects including pain, swallowing difficulties and fatigue reduced nutritional intake, food preparation and physical activity, although participants identified adaptations such as modified textures, ready meals, seated food preparation and family support. Professional participants emphasised that nutritional prehabilitation should be flexible, personalised and patient centred, taking account of individual priorities, motivations, appointment preferences, information needs and the personal relevance of nutritional preparation for each patient.

## Action Theme 4: Social connections- creating support and acceptance

This theme included peer support and social connections, family and caregiver support, personal adjustments and professional reflections on social connections. Lived experience participants described social connection as an important influence on motivation required for eating and supporting positive mental wellbeing. Living alone or finding it difficult to accept help made treatment harder to tolerate, while family, caregivers and peers could support

information gathering, reinforce nutrition plans and encourage engagement with nutritional prehabilitation. Participants also described the social impact of eating and drinking difficulties, including changes to family routines, eating out and confidence with food choices. Caregivers were viewed as a crucial source of practical and emotional support, but participants recognised that it could create burden and a sense of guilt caused by eating and enjoying food without difficulties. Professional participants supported the value of peer and group support but highlighted the need to consider timing, patient readiness and professional oversight to reduce misinformation

**Figure 3.** Lived experience and professional participants barriers (-) and enablers (+) for nutrition prehabilitation.

Table 2 insert here

Table 3 insert here

## Solution space

### Solution ideation and agreement

Lived experience participated ideated six preferred potential solution features; creating a joined-up continuum of care, education on the importance of nutrition and strength, a website/webpages, three key actions to do soon as possible, use of peer support groups, check how patients process information and coping style. These features responded directly to the action themes generated in the problem-space workshops (Table 4). Professional ranking identified education on importance of nutrition and strength (30%), continuum of care (27%), and being provided with three key action points as early as possible in diagnosis pathway (15%) as the top three priority solution features for inclusion in a nutrition prehabilitation intervention. This was followed by a prehabilitation webpage to host information (12%) (Fig. 4).

### Co-creation/design of prototype solution(s)

Three nutritional prehabilitation solution prototypes were co-designed and co-created (Table 5).

- Three key action points card
- A nutrition prehabilitation passport
- Education on the personal importance of nutrition and physical strength to support behaviour change.

The content of the three-action point card and passport were prioritised to support nutrition optimisation during the prehabilitation period. The prototypes were designed to address the identified key barrier and enabler action themes in relation to skills, knowledge, and motivation for nutrition prehabilitation.

#### Three key action points card

The three key actions point card was designed as a brief, accessible resource to be given to patients early in the pathway, either from diagnosis or when consenting to radiotherapy. The card is intended to support emotional and mental wellbeing by offering positive and practical actions that patients could begin immediately, thereby helping to restore a sense of control. It also addresses information accessibility and amount by presenting only brief, key messages. The three actions focus on optimising nutritional intake, being active and staying connected, thereby linking directly to the action themes of nutritional and physical wellbeing, emotional and mental wellbeing, and social connections. Co-creation participants intend for the card to help prepare patients for radiotherapy and support motivation to engage with nutritional prehabilitation.

#### Nutrition prehabilitation passport

The nutritional prehabilitation passport has been designed as an A5 patient-held booklet to be provided at the comprehensive nutritional prehabilitation assessment and used during subsequent review appointments. Co-creation participants contributed lived experience and professional expertise to determine the information included, prioritising practical, easy-to-read content that would help patients and caregivers understand the purpose of nutritional prehabilitation and optimise readiness for radiotherapy. To minimise repetition and information overload, topics already routinely covered elsewhere in the treatment pathway, such as dental care and swallowing management, were not included. Brief information relating to physical activity, emotional wellbeing and social connection is also included in the passport to reflect the other core pillars of prehabilitation and the action themes identified in the problem-space workshops. This includes information on being active, staying connected, looking after mental health and testimonials from previous HNC patients and caregivers.

#### Education on the personal importance of nutrition and strength to support behaviour change

The nutrition prehabilitation passport also provides a way to deliver the third solution: education on the personal importance of nutrition and strength to support behaviour change. It has been designed to record key assessment findings, including anthropometric, body composition and dietary information, and to support patient-centred goal setting, confidence rating, action planning, progress monitoring and feedback. This enables patients and dietitians to review and adapt goals over time, creating personalised interventions that align with individual priorities and motivations and support engagement with nutrition prehabilitation.

Overall feedback on the final prototypes was positive. Participants reported that the prototypes provided key information in an accessible format and conveyed hope and positivity. Within the nutritional prehabilitation passport, goal setting provided clarity about the aims and actions of nutritional prehabilitation, while practical components, including recipes, were considered useful. Minor amendments were made to selected words, phrases and images to improve accessibility and inclusivity. Examples of the prototypes are provided in Appendices 1 and 2.

Table 4  
Six potential solution features to support nutritional prehabilitation ideated by lived experience participants.

| Solution idea                                                                       | Linked action theme(s)                                                                                                                                                                                                           | Participant reflections/examples                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
|-------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1. Creating a joined-up continuum of care                                           | <ul style="list-style-type: none"> <li>• The care pathway</li> <li>• Information-accessibility &amp; amount</li> </ul>                                                                                                           | <ul style="list-style-type: none"> <li>• Prehab needs to be part of a continuum of care with information sharing- develop/give a 'Prehab passport'</li> <li>• Patients are unaware of available support</li> <li>• A care navigator would support care process</li> <li>• Hospitals are not communicating</li> </ul>                                                                                                                                                                                                                                                                                        |
| 2. Education on importance of nutrition and strength                                | <ul style="list-style-type: none"> <li>• Nutrition and physical wellbeing-demands &amp; impact</li> <li>• Information-accessibility &amp; amount</li> <li>• Emotional &amp; Mental wellbeing- demands &amp; impacts.</li> </ul>  | <ul style="list-style-type: none"> <li>• Needs to be more emphasis on strength as this is lost with weight loss.</li> <li>• Challenge the myth that weight loss is okay 'have a belly to lose', this comes both from patients and professionals</li> <li>• Need to know that it [nutrition &amp; protein] will help recovery and healing</li> <li>• Needs to be personalised – patient need to know why it [nutrition prehab] is important for them</li> </ul>                                                                                                                                              |
| 3. Create a prehab website / webpage                                                | <ul style="list-style-type: none"> <li>• Information-accessibility &amp; amount</li> </ul>                                                                                                                                       | <ul style="list-style-type: none"> <li>• Use the hospital HNC webpage to host and share information about prehab</li> <li>• Webpage could host a range of information including leaflet, videos, podcasts</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                        |
| 4. Provide with three key action points as soon as possible from point of diagnosis | <ul style="list-style-type: none"> <li>• Information - accessibility &amp; amount</li> <li>• Emotional and Mental Wellbeing- demands &amp; impact</li> <li>• Nutritional and Physical wellbeing-demands &amp; impacts</li> </ul> | <ul style="list-style-type: none"> <li>• Patients and caregivers want written information <i>"When stepping away from first meeting- when this is so important, take away three things, when you can't take on anything else at all"</i></li> <li>• Information needs to be positive</li> <li>• <i>"Being given positive things, absolute things that you can you do gives you something to hold onto when you are in that wilderness of not knowing what is going to happen to you. Saying 'you can do this this and this' gives you a little control back and that little bit of security"</i></li> </ul> |
| 5. Use of peer support groups/peer support                                          | <ul style="list-style-type: none"> <li>• Social connection-creating support &amp; acceptance</li> <li>• Emotional and mental wellbeing- demands &amp; impacts</li> </ul>                                                         | <ul style="list-style-type: none"> <li>• Create buddy system</li> <li>• Encourages patients to connect with others</li> <li>• <i>"At the time you don't want to talk to anyone- especially if you are used to your own company- but I did need help"</i></li> </ul>                                                                                                                                                                                                                                                                                                                                         |
| 6. Check how patients process information and their coping style                    | <ul style="list-style-type: none"> <li>• Information-accessibility &amp; access</li> <li>• Social connection-creating support &amp; acceptance</li> </ul>                                                                        | <ul style="list-style-type: none"> <li>• Be aware of information overload</li> <li>• Check patient current knowledge</li> <li>• Check they understand medical terms</li> <li>• Understand what else is happening in their real world i.e. social issues</li> </ul>                                                                                                                                                                                                                                                                                                                                          |

Table 5  
The three agreed nutritional prehabilitation solution features for co-creation

| Solution feature                                                                                     | Timing/use                                                                                                                      | Key components                                                                                                                                                                                                                                                                                                                                                                              | Intended function                                                                                                                                                           |
|------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>1. Three key action points for prehabilitation</b>                                                | Easy read card given at diagnosis or radiotherapy consent.                                                                      | <ul style="list-style-type: none"> <li>• Introduces the concept of nutrition prehab</li> <li>• Gives three key actions patients can start immediately to prepare for radiotherapy</li> </ul>                                                                                                                                                                                                | <ul style="list-style-type: none"> <li>• Provide health information while reducing information overload</li> <li>• Support motivation</li> </ul>                            |
| <b>2. Nutrition prehabilitation passport</b>                                                         | A patient-held booklet document provided & used during the dietetic prehab assessment and review appointment(s).                | <ul style="list-style-type: none"> <li>• Information about nutritional prehab</li> <li>• Patient clinical and social information</li> <li>• Practical nutrition information i.e. recipes and protein value of different food groups</li> <li>• Results/tracking of the prehab nutrition assessment plan and goals.</li> <li>• Brief information relating to other prehab pillars</li> </ul> | <ul style="list-style-type: none"> <li>• Provide key knowledge</li> <li>• Provide key skills</li> <li>• Support motivation</li> <li>• Support continuity of care</li> </ul> |
| <b>3. Education on the personal importance of nutrition and strength to support behaviour change</b> | Use the nutrition prehab passport to create a personalised nutrition care plan that explore patient priorities and motivations. | <ul style="list-style-type: none"> <li>• Use behaviour change strategies</li> <li>• Exploring importance &amp; confidence.</li> <li>• Setting of individualised goals and action planning</li> <li>• Opportunity to self-monitor</li> </ul>                                                                                                                                                 | <ul style="list-style-type: none"> <li>• Enhance motivation and opportunity to engage with and enact individual nutrition prehab care plan and goals.</li> </ul>            |

## Discussion

This study describes an iterative approach to understanding the key barriers and enablers for nutritional prehabilitation for HNC patients receiving radiotherapy, using these to facilitate the co-creation and development of innovative prototype solutions.

The problem space workshops demonstrated that nutritional prehabilitation is not only shaped by patient nutritional and physical needs but also how information is delivered, patient and caregiver motivation and emotional wellbeing, available patient support networks and the complexity of the care pathway.

While not all barriers and enablers could be addressed in a single intervention, having a deeper understanding of these facilitated practical problem solving and realistic solution ideation. This enabled our co-creation participants to prioritise solutions that could support patient empowerment, address pretreatment malnutrition and improve nutritional readiness of future patients before radiotherapy.

The resulting co-created intervention components consist of a three key actions point card, a nutrition prehabilitation passport and personalisation of the importance of nutrition prehabilitation to support behaviour change embedded within the passport and delivered by the dietitian during a comprehensive dietetic assessment.

## Comparison with previous studies

Although this study focused on understanding the barriers and enablers to support an iterative process of co-creation rather than conducting an in-depth thematic analysis, the experiences and action themes identified align with comprehensive qualitative studies of HNC treatment and nutrition (16, 17, 32–34). These studies describe the negative physical and social effects of nutrition-related side effects, highlight fractured care pathways, inconsistent timing of information, and gaps in professional support, with reference to dietetics. They also report patients longing for a “new normal”, emphasising the role of and impact on caregivers, and the value of shared experience through peer support.

There is a need for nutrition prehabilitation that helps to mitigate against the potential negative impact of radiotherapy on nutritional status both short and long term. Conducting 135 patient interviews at regular intervals for up to two years post radiotherapy treatment Einarsson et al. (2019) sought to gain long term insights into the nutritional impact of treatment (32). Their analysis described how patients experience and cope with nutritional related difficulties which can be defined as three interrelated concerns, the persistent effort required to eat and drink, the social and emotional consequences of altered eating and the gradual process of adapting to a changed everyday life, the “new normal”. These concerns closely align with our action themes, *Nutritional and Physical Wellbeing—impact and demands*, *Emotional and Mental Wellbeing—demands and impacts*, and *Social connections—creating support and acceptance*, suggesting that the issues raised during our co-creation are consistent with the literature and importantly that these issues are not solely isolated to prehabilitation interventions but are also reflected throughout survivorship.

Our study findings reinforced the importance of personalised, patient centred, assessment and dietary advice, to help patients understand the benefits of prehabilitation and optimising their nutritional status. This finding is supported by other qualitative evidence (16, 17) and interventional studies demonstrating the benefit of dietitian-led counselling over generic advice in mitigating against weight loss (35–38). Sandmael *et al.* (2019) highlights the need for individually tailored dietitian-led nutritional care to be integrated into HNC pathways (17). They described the “waiting to get started phase” (prehabilitation phase) where patients received generic advice with no associated action. Our participants highlighted the importance of taking action during the prehabilitation phase in preparation for the physical and nutritional demands of treatment, particularly the risk of weight and strength loss.

Our findings demonstrate the importance of accessible, timely information, while also recognising the risk of information overload during treatment preparation. This risk is well established in cancer care (39, 40) and our participants emphasised the need to balance essential information with the capacity for action. Similarly, Sandmael *et al.* (2019) reported that patients may struggle to absorb pre radiotherapy information and suggested earlier peer support (17). In our study this aligns with *social connections- creating support and acceptance* as a key action theme for enabling nutrition prehabilitation.

While the design and purpose of the prototype solution was driven by the experience and expertise of the co-creation participants, they are consistent with wider evidence and clinical guidance supporting patient-centred, accessible and behaviourally informed approaches to nutritional prehabilitation. The proposed three key actions point card reflects evidence that simple tools which focus on three points or questions can support health literacy, reduce cognitive overload and promote informed patient involvement in care (41–43). Similar approaches underpin the Institute for Health Improvement Ask Me 3 campaign and the NHS England shared decision-making programme (44, 45). However there remains concerns that such tools may be less accessible for people with lower health literacy, highlighting the need for careful adaptation (46). In our study the three actions card was co-created with lived experience and professional participants with regular reflection and review of language and accessibility to minimise risk.

The co-designed nutrition prehabilitation passport also aligns with the established use of patient-held records and health passports, which aim to empower patients, support personalised patient centred care and improve continuity of care across services through information sharing (47–50). Evidence for patient-held records in cancer care remains mixed, with findings from a systematic review limited by variation in study design and implementation (51). However, evaluation of a HNC-specific logbook found that patients using the resource were better informed, more supported and involved in their care, although its size and professional engagement affected its acceptability and sustainability (52). Feedback suggested that A4 size was too bulky, this was equally reported by our co-creation participants with agreement that A5 format would be more practical for our Co-ENHANCE nutrition prehabilitation passport.

Personalisation and supporting behaviour change within our Co-ENHANCE intervention components is also underpinned by evidence. The Getting it Right First Time (GIRFT) report and prehabilitation guidance emphasise that nutrition interventions should address the cause of nutritional risk, be centred on shared goals and incorporate strategies to support behaviour change (6, 18, 22, 53, 54). The COM-B model (capability, opportunity motivation-behaviour) provides a framework for understanding and designing interventions that support lifestyle and behaviour change modifications. The model proposes that capability, opportunity, and motivation are essential conditions for behaviour change (55). Our Participants highlighted the relevance of these components for HNC nutrition prehabilitation, emphasising the need for clear and meaningful information, accessible pathways, and motivation to engage at a time when diagnosis can negatively affect mental health. The passport is intended to operationalise these principles through behaviour change techniques such as individual goal setting, confidence rating, action planning and progress monitoring and feedback. In doing so, it will address a recognised gap in malnutrition interventions where individual barriers to behaviour change and behavioural outcome are often poorly explored (56).

Together, these prototype solutions will be delivered as part of an individual comprehensive nutritional prehabilitation assessment supporting the sub theme of our study *making it patient centred*. They also reflect wider HNC guidelines that advocates for holistic assessments, shared decision-making, collaborative multi-disciplinary working, wellbeing support and access to peer support and align with the recognition that for prehabilitation and HNC there is no One-size-fits-all approach (18, 54).

## Implication for future research

This study describes the first work package of the Co ENHANCE study, the investigation of a **co-produced nutritional prehabilitation intervention in head and neck cancer patients treated with radiotherapy (+/- chemotherapy)** (57). The second work package aligns with the testing (including evaluation) and considerations for the subsequent deployment space (long term implementation) following the LLIP. Here the developed prototype solutions will be tested and evaluated as part of a feasibility study delivered in an NHS setting.

## Strengths and Limitations

This study had several strengths. The co-design approach ensured consensus across all lived experience and professional participants ensuring that multiple perspectives informed the interventions. The study also included participants with more recent treatment experience helping to maintain relevance to current practice. Although resource and time constraints limited development of digital components such as videos and websites and digital passport, the decision to test paper-based prototypes may improve inclusivity given the lower level of digital literacy reported amongst some HNC populations. However, several limitations should be considered. This study involved a small cohort of participants. While attempts were made to recruit widely, selection bias remains possible as those who are more motivated and confident may be more likely to engage with research. This may limit how well the findings and outputs represent the wider HNC population, which are known to experience higher levels of socioeconomic deprivation (58). Delays with site set up-reduced access to a large patient identification centre. This restricted our efforts to recruit and engage more diverse patient and caregiver participants from underserved backgrounds. Engagement with some participants declined across the study phases due to personal and professional commitments. Participants were regularly asked about any support needs and invited to provide email feedback with meeting attendance was not possible. Most lived experience participants completed treatment more than five years ago. As care pathways, routine treatment and dietetic provision, may have changed during this period, their experiences may not fully reflect current practice, gaps or potential opportunities /solutions for nutrition prehabilitation.

## Conclusion

Our study demonstrates that the key barriers and enablers for nutritional prehabilitation centre around the balance of information, personal prioritisation of nutrition, harnessing motivation, patient centred nutritional care plans and finding ways to deliver and adhere to nutrition prehabilitation within a complex care pathway. Our Living Labs co-design approach fostered shared power and ownership, enabling participants to co-design a range of solutions, The resulting intervention prototypes comprise a three key action points card, a nutrition prehabilitation passport and education on the personal importance of nutrition and strength delivered within a comprehensive dietetic assessment and review appointments to support behaviour change. When tested this will be one of the first research studies in the UK to offer nutritional prehabilitation before HNC radiotherapy, using co-designed solutions. If successful, this could improve patient readiness and tolerance to treatment and mitigate against significant weight and muscle loss and the negative impact on QoL.

## Abbreviations

Co ENHANCE

**Co**-creation of a nutrition prehabilitation intervention in **head and neck cancer** patients treated with radiotherapy (+/-chemotherapy)

HNC

Head and neck cancer

LL

Living Labs

LLIP

Living Labs Integrative care process

MDT

multidisciplinary team

NHS

National Health Service

NIHR

National institute of health and care research

OT

Occupational therapist

PHR

Patient held records

PPIE

Patient and public involvement and engagement

Prehab

Prehabilitation

QoL

Quality of life

## Declarations

## Ethics approval and consent

This study received ethical approval from the Health Research Authority, Wales Research Ethics Committee 7 reference number 25/WA.0162. IRAS project number 336133. Participant information sheets were provided to all interested participants, and informed signed consent was obtained from all co-creation participants taking part in the workshops.

## Consent for publication

All participants involved completed informed consent.

## Competing interests

The authors declare no competing interests

## Authors information

Linda A. Cantwell (corresponding author), University of Liverpool, Mersey Care NHS Foundation Trust

Professor Joanne M. Patterson, University of Liverpool

Dr Grahame Smith, Liverpool John Moores University

Dr Mary Gemma Cherry, University of Liverpool

Professor Nefyn Williams, University of Liverpool

Co-ENHANCE PPIE steering group – (Alison Bryant PPIE lived experience researcher, Saiqa Ahmed, Greg Hunt, Carol Hunt)

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## Author Contribution

Development of protocol: LC, JP, NW, MGC, GS. Project Lead: LC. Development of study material, data analysis and interpretation: LC, JP, NW, MGC, GS, Co-ENHANCE PPIE steering group, Writing of main manuscript: LC. Critical review and manuscript revision: JP, NW, MGC, GS, Co-ENHANCE PPIE Steering group. All authors reviewed the manuscript.

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## Data Availability

Data supporting the findings of the study are reported within the manuscript paper. The co-designed intervention solution prototypes; the Co-ENHANCE three key action points card and nutrition prehabilitation passport are available in the appendix as supplementary material. Those interested in their use should contact the lead researcher and acknowledge their original source.

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## Figures

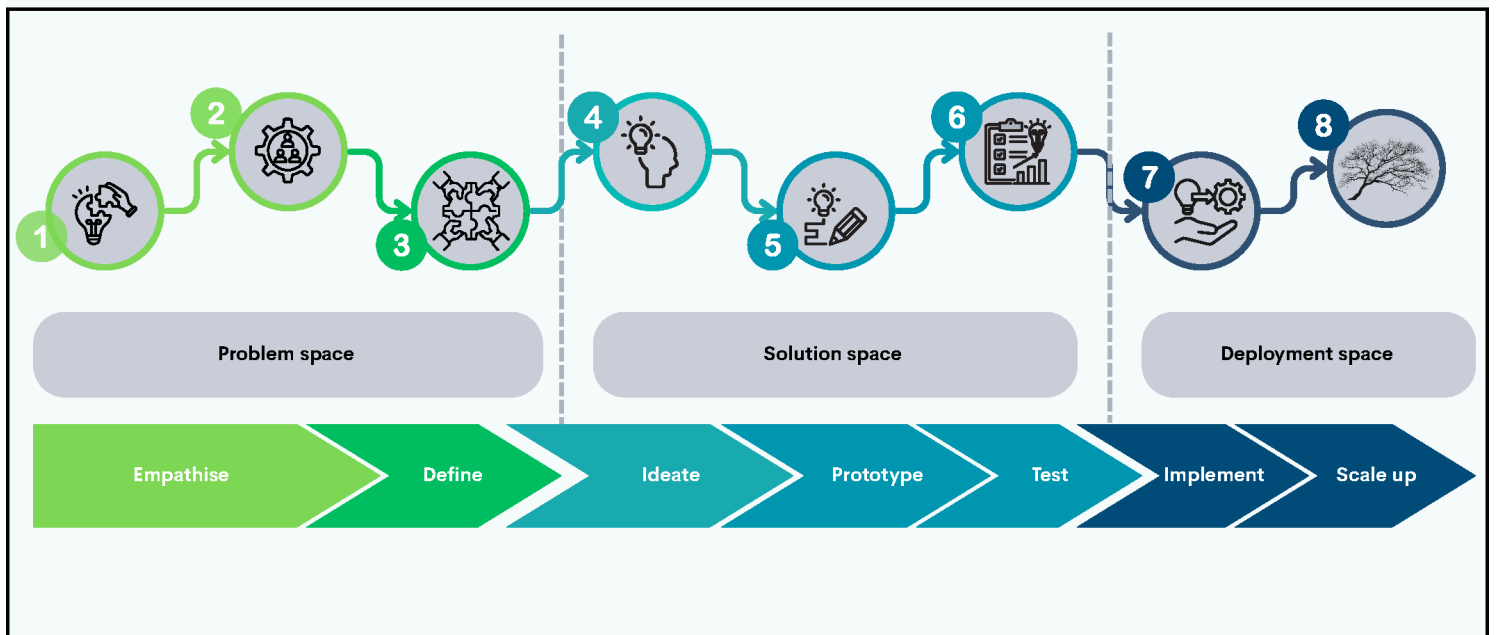


Figure 1

Living Lab Integrative Care Process adapted from Mastelic, 2019 (30)

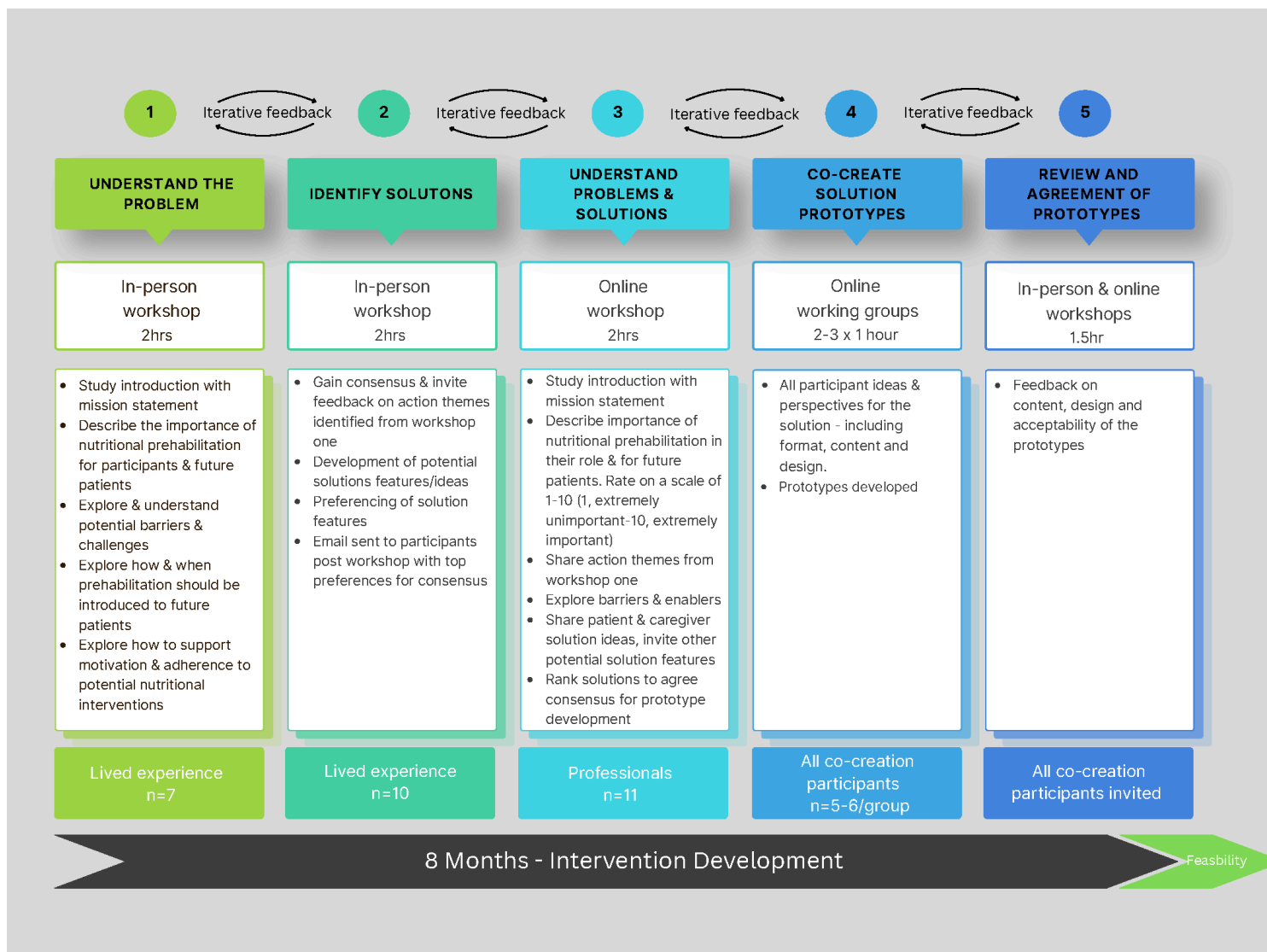


**Figure 2**

The iterative phases of our Co-ENHANCE Living Labs Integrative Care Process starting with the problem space through to solution spaces to co-create solution prototypes. Including topic guide information and outline of each workshop or working group meeting. Next phase not included in this study; prototype testing and deployment space.

| Information - accessibility & amount                  |                                                                                                           |
|------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------|
| Lived experience                                                                                                                         | Key information (+)      Lack of information (-)      Information uncertainty (+/-)                       |
| Professionals                                                                                                                            | Information overload (-)      Evidence (-/+)                                                              |
| Emotional & Mental Wellbeing - demands & impacts      |                                                                                                           |
| Lived experience                                                                                                                         | Motivation (+/-)      Control (+/-)      Psychological impact (-)                                         |
| Professionals                                                                                                                            | Emotional support (+)                                                                                     |
| Nutritional & Physical wellbeing - demands & impacts  |                                                                                                           |
| Lived experience                                                                                                                         | Being strong (+)      Managing side effects (-)                                                           |
| Professionals                                                                                                                            | Patient centred (+)                                                                                       |
| Social Connections - creating support & acceptance    |                                                                                                           |
| Lived experience                                                                                                                         | Personal adjustments (+/-)      Family & caregiver support (+)      Peer support & social connections (+) |
| Professionals                                                                                                                            | Social connections (+)                                                                                    |
| Care pathway                                         |                                                                                                           |
| Lived experience                                                                                                                         | Disjointed Care (-)                                                                                       |
| Professionals                                                                                                                            | Financial (-)      Continuity of care (+)      Timing & access (-)      Centralised services (-)          |

**Figure 3**

Lived experience and professional participants barriers (-) and enablers (+) for nutrition prehabilitation.

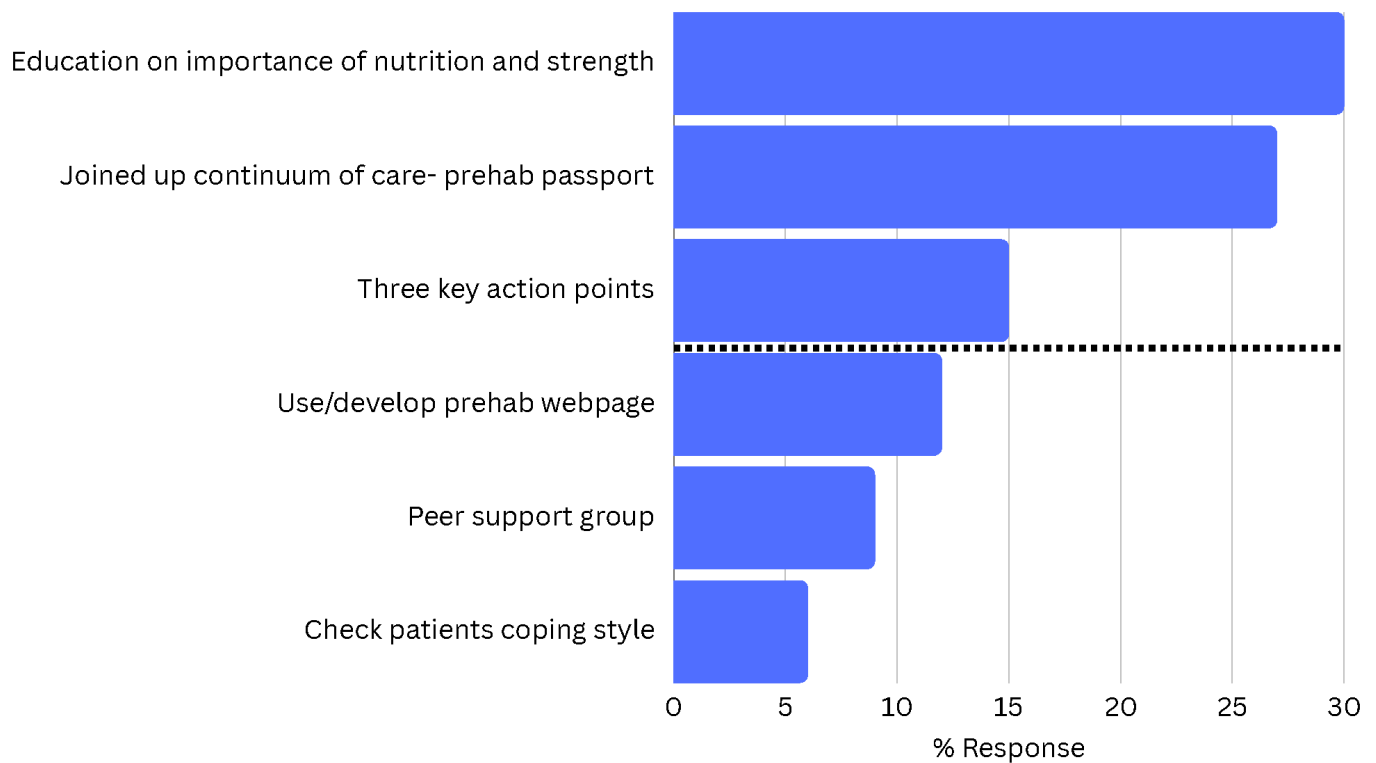


**Figure 4**

Professional participant ranking of proposed nutrition prehabilitation solutions for HNC radiotherapy.

## Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [Appendix1ThreeKeyActionPointsCard.pdf](#)
- [Appendix2Nutritionprehabpassport.pdf](#)
- [Table2Livedexperienceparticipantquotationfinal23.9.26.docx](#)
- [Table3professionalparticipantquotationfinal.docx](#)