

Maggie's Prehab Pilot

Final report to Scottish Government

April 2023



Introduction and purpose of the report

Maggie's is a network of cancer centres providing emotional and practical support to anyone with cancer, their friends and family. Scottish Government funded Maggie's to plan, prepare and deliver a universal prehabilitation pilot in all eight of its Scottish centres from June 2021 to March 2023.

The purpose of this report is to;

- assess the success and impact of the pilot
- identify challenges and lessons learned throughout the pilot period

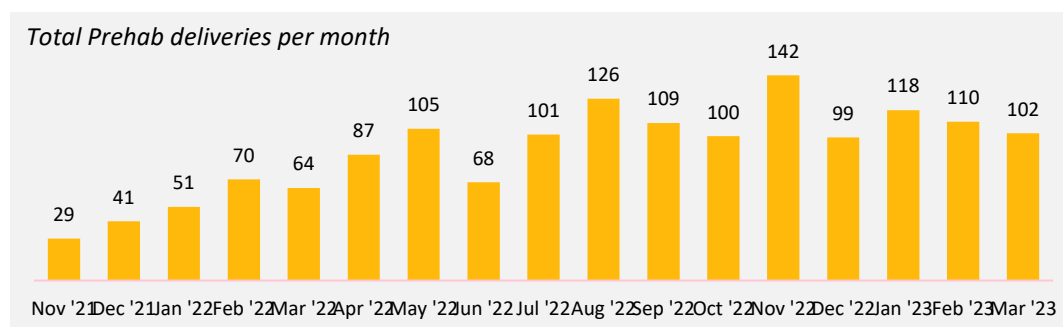
Background

Scottish Government commissioned Maggie's to provide universal prehab sessions - that is, suitable for all people with cancer – integrated within the cancer patient pathway to complement NHS clinical treatment and support.

The total grant agreed was £269,677. This funded the development, delivery, project management and evaluation of prehab project, along with the production of local marketing materials for each centre, and eight promotional 5-minute films. As an example, the film for the Fife centre can be seen here: <https://www.youtube.com/watch?v=zK8LHBjxK-0>

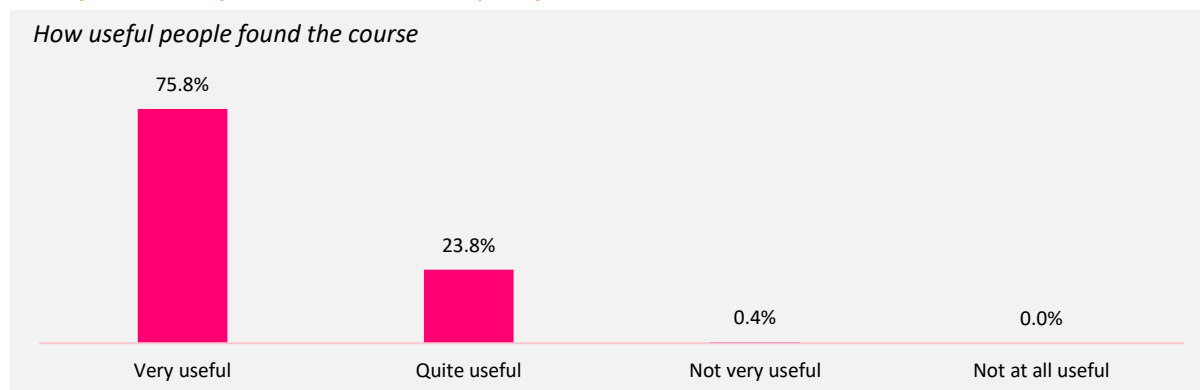
We delivered universal prehab support from all eight Maggie's centres in Scotland, which are located at all five major NHS cancer centres, the satellite cancer centre at Lanarkshire and cancer units in Fife and Forth Valley, aligned with the Scottish Government's Right to Health equal access approach.

Between November 2021, when delivery started, and March 2023, Maggie's supported a total of 1522 people with cancer and their friends and families through the universal prehab project.



Out of 1,522 deliveries, 130 (9%) were completed online. All of these sessions were provided by our Highlands centre, owing to its unique situation of supporting those from very widespread and remote geographical locations.

76% of attendees found the course “very useful”



Implementation of the pilot

Following extensive consultation, development and planning, Maggie's agreed and produced presentation materials (in consultation with others) and trained their staff to deliver the prehab offer. Delivery started in November 2021. Maggie's took a phased-start approach, with three centres starting at the outset, building up to all eight centres delivering by April 2022. Implementation was slowed by the on-going impact of the pandemic, as it was difficult to develop referral relationships with overstretched NHS clinical staff. In addition, activity was limited within Maggie's, as we had to adhere to Covid restrictions, had reduced staffing capacity and had to consider the needs and concerns of Covid-vulnerable cancer patients.

Initially centres started delivering to specific cancer site groups. For example

- Maggie's Fife focused on people with colorectal cancer
- Maggie's Edinburgh focused on those with a diagnosis of advanced lung cancer.

However, by the end of the pilot, prehab sessions were open to people with any type of cancer, at any stage, with any prognosis.

Maggie's universal prehab support focused on emotional, nutritional and physical activity support, helping people to identify potential behavioural changes and to develop the motivation to make them happen. Prehab sessions at Maggie's are delivered by our expert staff including Cancer Support Specialists, complemented by external sessional expertise where needed, including specialist NHS teams.

Our prehab support is delivered ideally to small groups, enabling discussion and peer support, although some centres also provided support on a one-to-one basis. The aim of the sessions is to introduce prehab as a concept, highlight the impact it can make, and to encourage people with cancer to take action for themselves - developing new habits around their emotional health and

ability to cope, their nutrition needs and their physical activity. The workshop is designed for people with cancer to actively participate and engage in their care.

Optimally, prehab support is delivered to people shortly following a cancer diagnosis and before treatment starts, enabling people to be as physically well and mentally prepared for treatment as possible. As a result, Maggie's relies heavily on the partnership with the NHS and good collaborative relationships with individual clinical staff and teams to promote, engage and refer people to the universal prehab sessions.

Through the pilot, Maggie's was able to offer a weekly prehab support session to ten people with cancer, at every centre. We knew this was a stretch target and the pilot has confirmed this – we do have the capacity to deliver this level of activity, but referrals from Health Board colleagues have not reached these levels. This is explored further in the “Challenges and lessons learnt” section.

Our successes

- The number of people supported through prehab has steadily increased since the beginning
- Our flexible approach means support has been available in groups as well as one one-to-one
- We were able to support people with any cancer diagnosis
- We are also supporting carers and family members (a need identified by the Focus Groups)
- Prehab acted as an entryway to the wider cancer support on offer at Maggie's, which people with cancer and their carers can access for free and for as long as they need. We also referred to other sources of support in the community, ensuring people with cancer had the information they need to get as much support as possible.
- As some centres, we have developed effective referral routes with NHS teams/colleagues. For example, Maggie's Glasgow works closely with the oncology anaesthetists, and Maggie's Aberdeen developed a good relationship with a senior colorectal surgeon, both of whom ensured that Maggie's prehab offer was a regular item on the multi-disciplinary team meeting agenda.

Monitoring and evaluation

We monitored up-take of the pilot project quantitatively, and evaluated it qualitatively, in terms of both visitor experience and the quality and consistency of delivery.

Data monitoring

Maggie's staff recorded attendance at prehab sessions using a Personal ID number (PID), stored separately from their personal details. With a PID, we could track any return visits to Maggie's made by a person attending a prehab session, and this gave us a clear idea of post-prehab engagement.

Our data suggested that approximately 41% of people attending a prehab session returned to Maggie's for further support, either immediately or at a later stage. People returning when they are

in the middle of their (busy) treatment regime is testament to the value they attached to the support Maggie's provides.

62% of those who returned came back to access emotional and psychological support.

Aside from emotional support, people also returned to Maggie's for a variety of additional support including:

- Welfare and benefits advice to maximise household income – more timely than ever during the cost-of-living crisis.
- Our "Getting Started" courses, which outline various treatments and help people with cancer to understand what comes next after diagnosis
- Groups for specific cancer site diagnoses e.g. colorectal and haematology
- Help on talking to children about cancer

Through this universal prehab pilot, Maggie's have been able to support more people at the start of their cancer experience; as a result, those attending had access to support that they may not have known was available.

Evaluation

Maggie's used a multi-strand process of evaluation for the prehab pilot. Further detail on the evaluation process is included in the evaluation information at Appendix 1, and a case study story at Appendix 2. Feedback showed that people immensely valued the support they got from Maggie's, both through prehab workshops and through the ongoing additional support they could access. After prehab workshops, 77% reported a positive impact on their health engagement.

Challenges and lessons learnt from the pilot

Referral pathway

As above, our initial aim was to support ten people per week at each centre (80 people per week). We had the capacity to do this at most centres, but that capacity was rarely fully utilised. A contributing challenge was the need to engage health board clinical teams and ensure they referred people to us at point of diagnosis. We used our existing contacts at the start of the pilot, contacting NHS colleagues who were already familiar to Maggie's and then approaching others. In practice, this meant developing relationships with individual clinicians and teams from one discipline (cancer site) at a time.

This proved time-consuming - Maggie's staff were in constant communication with clinical teams and had great success with some teams but struggled with others. We found that many healthcare professionals

- do not fully understand the concept of prehab or the value it can bring to people with cancer
- are sceptical of the complementary role the third sector can play, and
- are sometimes reluctant to refer to or endorse Maggie's prehab offer to their patients (in some instances, despite there being no other prehab offer available).

To address this, throughout the pilot Maggie's staff worked hard to promote our prehab offer and its merits in various talks and meetings with individual clinicians and clinical teams (MDTs), as well as strategic and national groups such as Nurse Consultants meetings, TCC delivery Group and ICJ/Move More.

The pilot has proved that identifying a senior clinician who can endorse Maggie's prehab offer is of greatest value in establishing referral pathways, and ensuring a steady flow of newly diagnosed patients into Maggie's. However, it is acknowledged that it takes time to build up these relationships with NHS colleagues, which by their very nature are dependent on individuals, even with robust referral patterns/criteria. Increased support and engagements from Scottish Government and senior staff and clinical leads within the Health Board is essential to improve referral pathways and utilisation of capacity.

Covid

Covid has had an inevitable impact on the delivery of the Maggie's prehab pilot in a number of different ways including;

- our ability to engage NHS teams to get sufficient numbers through the pilot
- people with cancer and their families, who may still be shielding,
- staffing capacity with Maggie's and the NHS

The NHS continues to experience many challenges with the continued impact of Covid - developing effective relationships between Maggie's and the clinical teams has been difficult under these circumstances. We know however that the Maggie's prehab sessions can play a small part in relieving pressure on overstretched NHS staff, if we can improve the referral pathways and increase the number of patients accessing the sessions. We look forward to continuing to work with Scottish Government and our NHS partners on prehab going forward.

Appendix 1 - Going forward

We want to continue to work in partnership with Scottish Government to demonstrate the value and effectiveness of prehab, not just in the immediate value felt by people with cancer and their families/carers attending sessions, but also its longer-term impact. We want to positively exit out of 'pilot' phase and establish a sustainable programme that is well understood by clinicians and patients and is fully utilised.

Scottish Government have agreed to one year continuation funding, from 1 April 2023 to 31 March 2024 (at a value of £80,000), to enable us to further develop our success in more usual non-Covid circumstances, and to build on the extensive work we have already put in to develop more robust referral pathways and more collaborative working with NHS Clinical teams. Maggie's is confident that this additional funding will enable us to support at least 1500 more people (in 2023/24) and build our capacity to support individual needs throughout the whole patient pathway from prehab to rehab using Maggie's whole programme. This will support the objectives of the Scottish Government's wider cancer prehab programme and contribute towards the aims and ambitions set out in their forthcoming strategy.

Maggie's contribution to wider strategy from 2023 onwards

Inputs	Activities	Outputs	Short term outcomes (3 years)	Mid term outcomes (6 years)	Long term outcomes (10 years)
<p>One year of funding to Maggie's from SG</p> <p>Engagement from NHS Education Scotland (NES) and wider partners</p>	<ul style="list-style-type: none"> • A weekly universal prehab workshop in each centre in Scotland with ongoing evaluation and quality improvement processes in-built • Create handout materials and booklets for prehab attendees • Continued promotion via social media • Review and assess the online prehabilitation offer versus the face to face workshop • Continue to work jointly with NHS colleagues and work towards more formal collaboration • Create a train the trainer toolkit for other to replicate and deliver workshops 	<ul style="list-style-type: none"> • Robust and sustained universal prehab offering available in each centre • High quality and evidence-based materials that support positive outcomes available to attendees • Agreed pathways of care and processes that allow equitable and timely access to the prehab workshops at Maggie's • Training and tools available to those that wish to deliver the Maggie's prehab workshop via their own organisation 	<p>Wider coverage of universal prehab services across Scotland (through train the trainer), with services sustained in Maggie's Centres</p> <ul style="list-style-type: none"> • Data about availability, uptake and impact of universal prehabilitation in Scotland available to support demand and capacity modelling • Greater understanding of the potential of universal prehab and reduced unwarranted variation • Improved knowledge, skills and understanding of prehab across Scotland 	<p>Co-ordinated cross sector services delivering prehab across Scotland maximising capacity to address demand and delivering positive individual and systems level outcomes</p>	<p>Sustainable person centred multi-modal prehab embedded within relevant cancer pathways across Scotland with long-term data informing approach</p>

Appendix 2 - Prehab Evaluation

Aims

The aim of the evaluation was to determine whether prehab had enabled people with cancer, and their friends/family members/carers to make positive changes to their emotional well-being, physical activity, and diet/nutrition. We also wanted to know if attendees felt more engaged in their treatment and wider health decisions post-prehab.

Method

Attendees of the prehab programme were given a feedback survey to complete at the end of the session. The survey contained questions on their engagement with health; their confidence in making positive changes to their emotional, physical, and nutritional well-being going forwards; and general course feedback.

Some provided their email address to take part in an in-depth interview, and some completed a post-prehab survey six weeks or more after the session.

Personal identification numbers (PIDs) were assigned to each person who completed a form, and their activities at Maggie's following prehab were recorded.

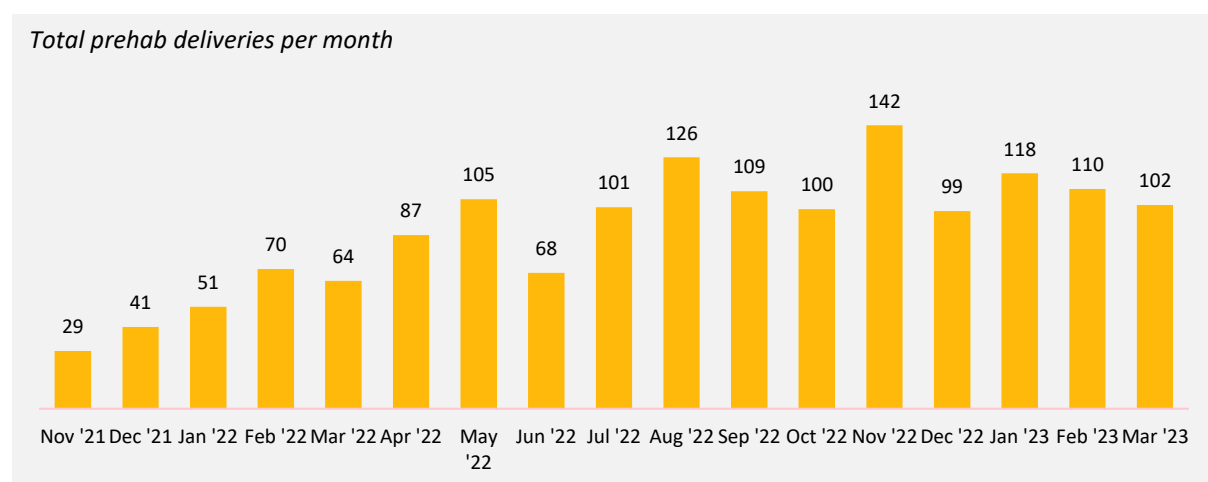
Prehab attendance

Prehab was delivered to 1,522 people

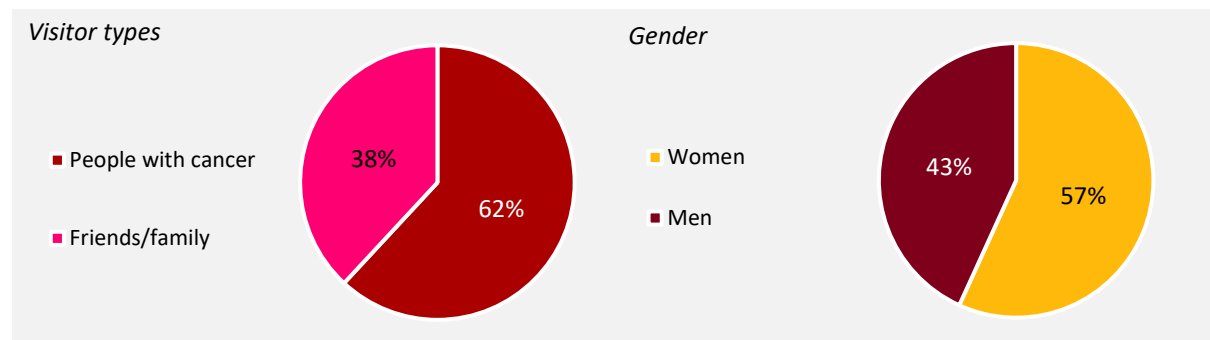
Prehab roll-out was staggered across the eight centres as follows:

Nov 2021	Jan 2022	Feb 2022	Apr 2021
Fife	Gartnavel	Forth Valley	Aberdeen
Dundee	Lanarkshire	Highlands	
Edinburgh			

Between November 2021 and March 2023, 1,522 people attended a prehab session.



Nearly two-thirds (62%) of attendees were people with cancer, and just over half (57%) were women.



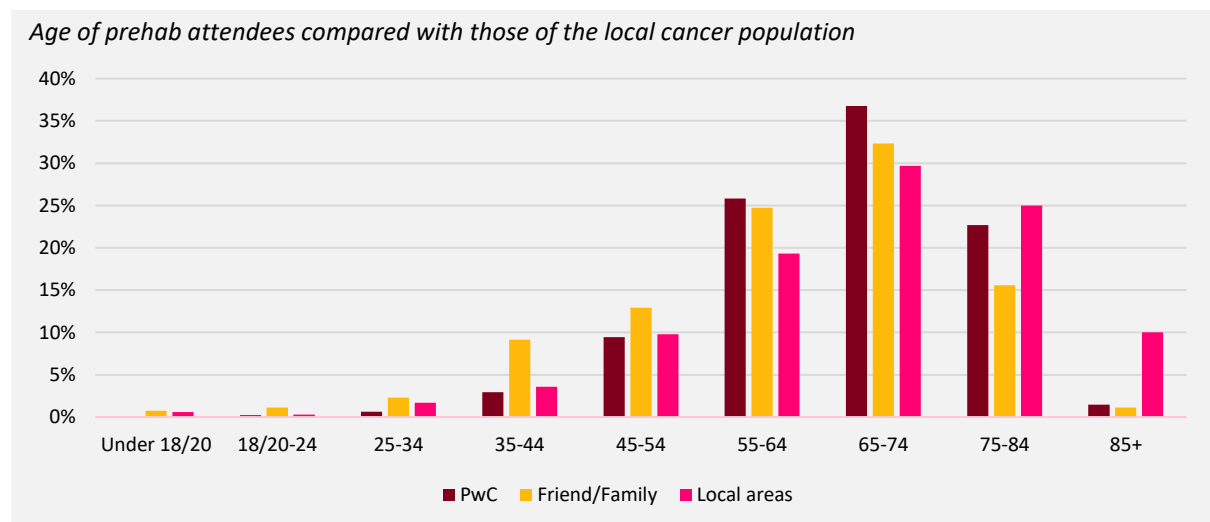
130 people accessed prehab online

Out of 1,522 deliveries, 130 (9%) were completed online. All of these sessions were provided by our Highlands centre, owing to its unique situation of supporting those from very widespread and remote geographical locations.

Feedback analysis

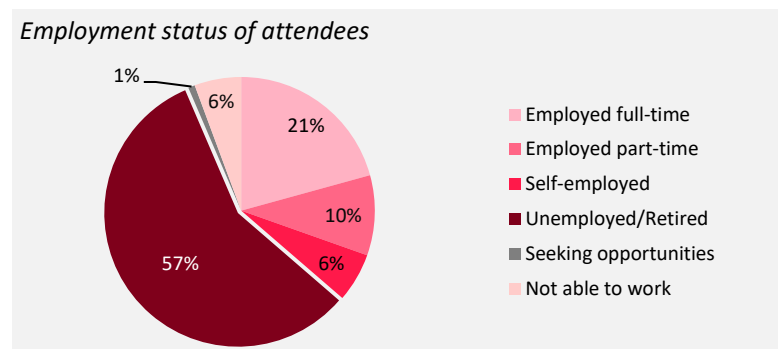
We received 768 responses, giving a response rate of 50%.

Prehab attendees tend to be younger than those seen in the local cancer population



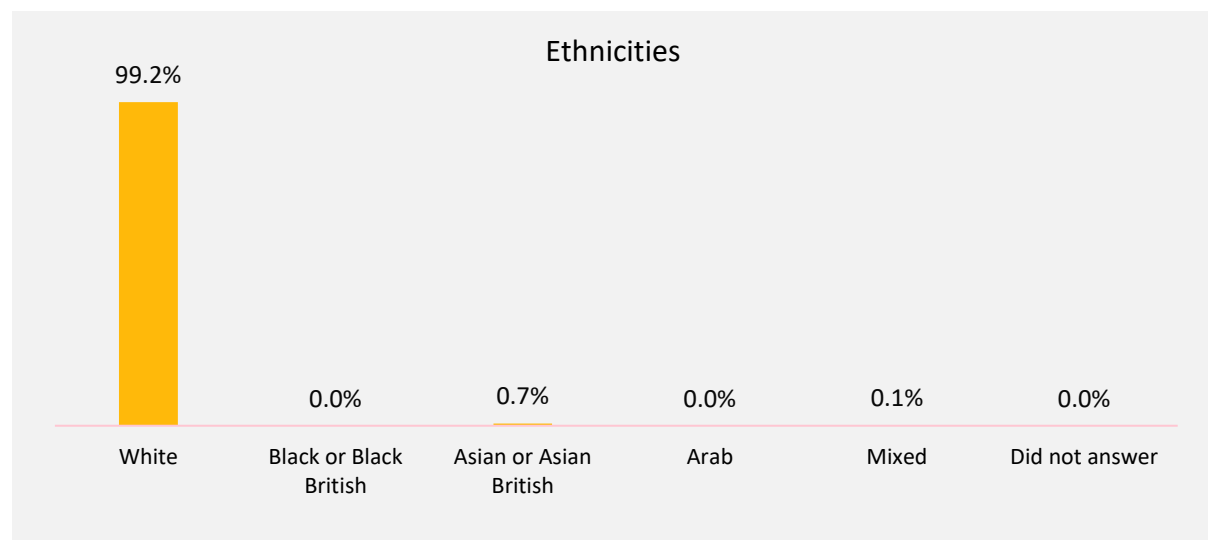
63% of people with cancer attending were between 55-74 years of age, compared with 49% of the local cancer population being the same age¹.

Over half of attendees are unemployed or retired



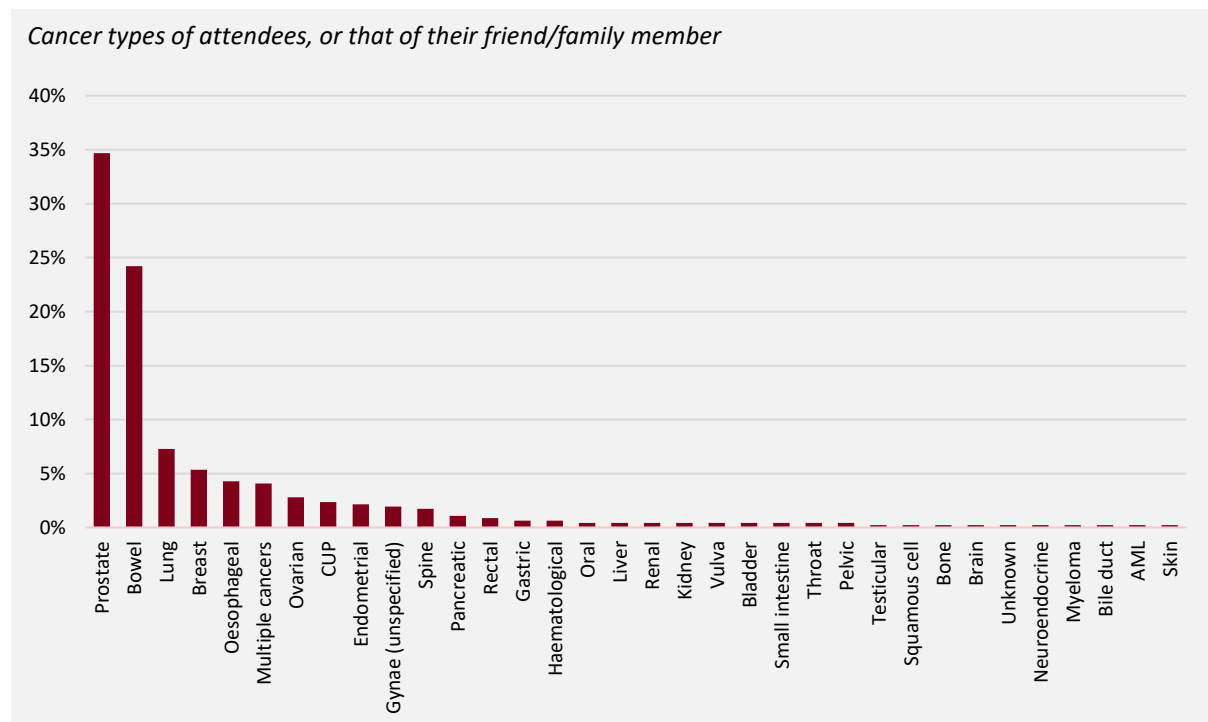
This is true for both people with cancer and friends/family members.

99% of prehab attendees are white



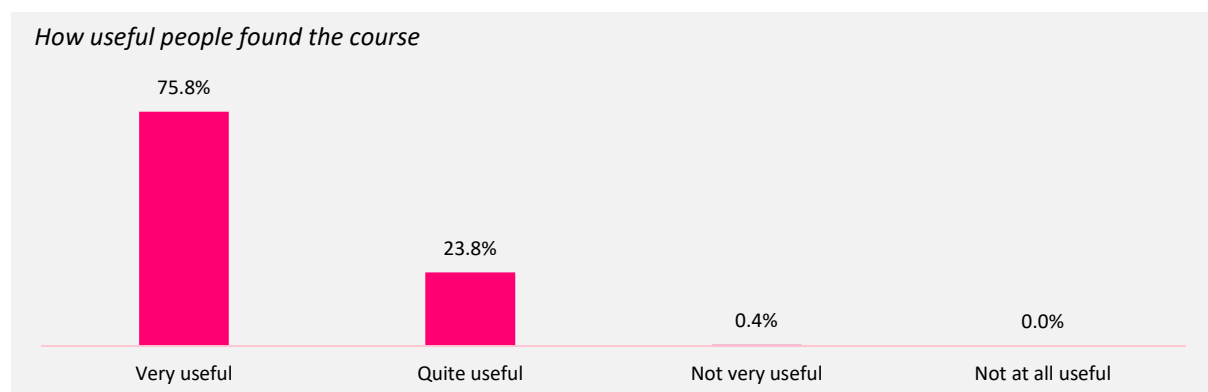
The local population of Scotland from the 2011 Census showed 96% of the population were White, and 4% from Asian, Black, Mixed, and other ethnic groups². We are slightly under-representative of non-white communities.

Prehab has been delivered to people (or their families and friends) with many different cancer types



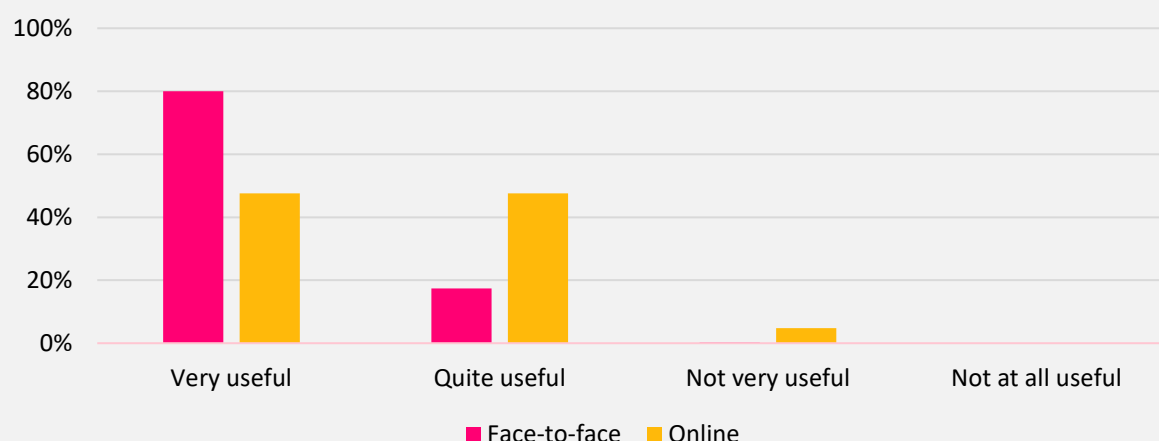
59% of deliveries have been to people with prostate and bowel cancers. At the start, each centre concentrated on getting referrals from one cancer type. However, as the sessions went on, more referrals came from different oncology units. We have so far delivered prehab to people with 34 different cancer types, including those who have multiple cancers.

76% of attendees found the course “very useful”



There was a difference in how useful the course was described as between those who attended face-to-face compared with those who attended online.

How useful prehab was, online compared with face-to-face delivery



While 80% of those who attended face-to-face said they found the course “very useful”, 48% of those who attended online said the same (although 96% reported it as useful overall).

From the qualitative analysis, certain themes arose on what people found the most useful. They learnt practical ways in which they could help themselves or those they care for.

“I thought the session was very educational. I feel I have support for myself going forward and better equipped to cope”

As they became more familiar with what was to come in terms of treatment, they felt less anxious about the future.

“It is run by people with intimate knowledge of the process I’m going through. V. reassuring”

Finding a supportive space at Maggie’s helped them to know they were not alone, and could return should they have any questions, concerns, or advice in the future.

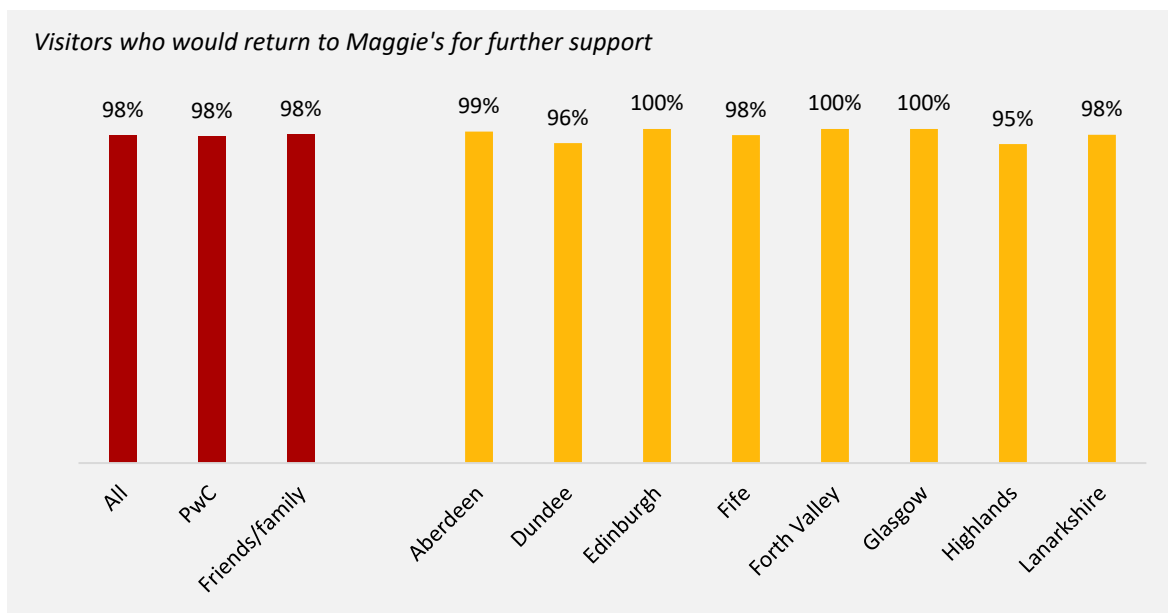
“I have felt very welcome coming here and think I will be a regular here now through my cancer journey. Everyone has been so friendly and very informative”

Meeting others in the same situation as them also helped them to feel less alone, and enabled them to normalise and talk openly about their feelings.

“talking over our feelings with understanding people”

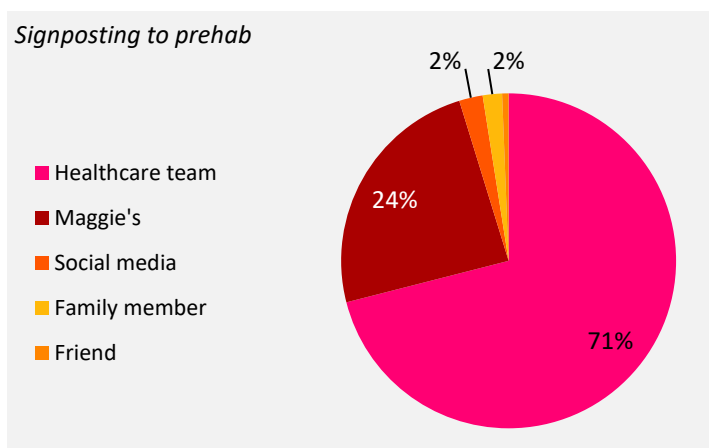
“sharing with others who are in a similar situation”

More than 95% of attendees said they would return to Maggie's for further support



Across all visitor types and centres, a high proportion of our attendees said they would access Maggie's again for further support. This was lowest in the Highlands (95%), to be expected as many live in remote areas and attended online.

Most hear about prehab through their healthcare team



71% of our attendees hear about prehab through their healthcare team. Our relationships with oncology teams in the NHS are therefore important for referral into our sessions.

Questions on health engagement

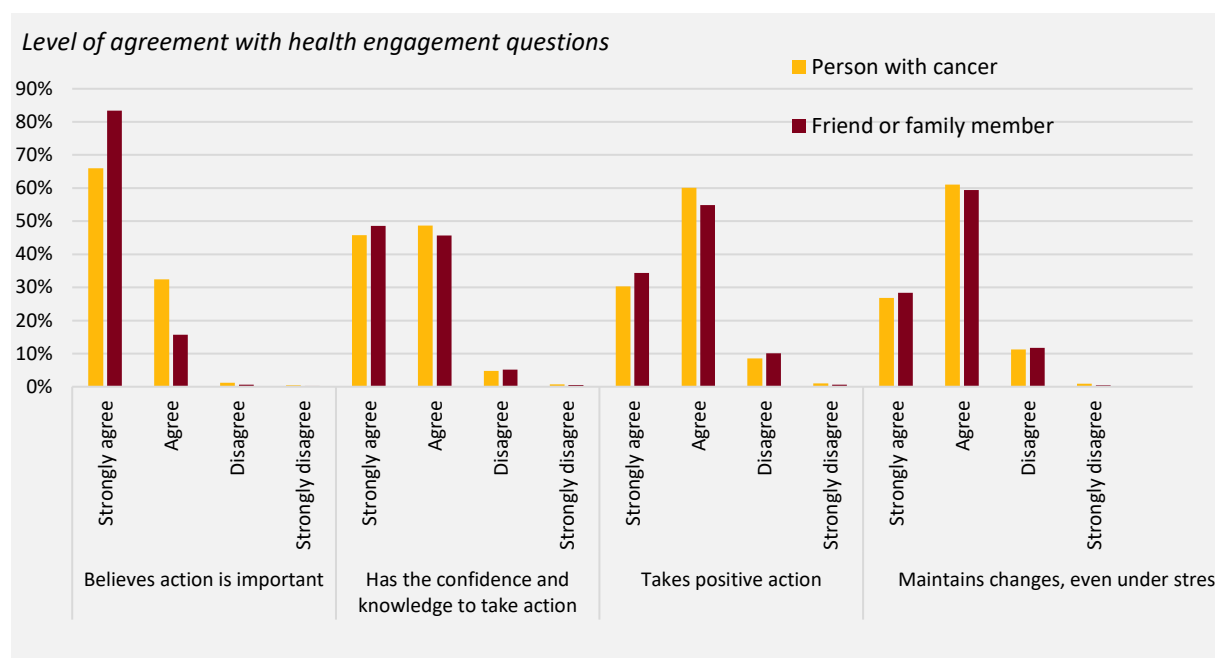
Questions on health engagement were taken and adapted from the Patient Activation Measure, to understand how engaged our visitors are with their health.

We asked 12 questions, which can be divided into the following domains:

- Believing positive action is important

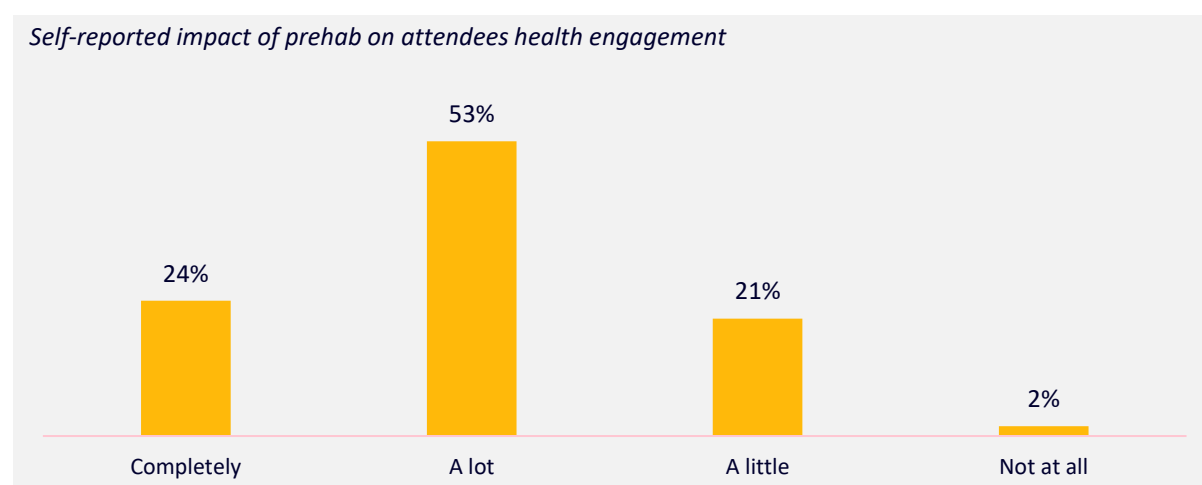
- Having the confidence and knowledge to take positive action
- Making positive changes
- Maintaining those changes, even under stress

Health engagement is positive in all domains, across all visitor types



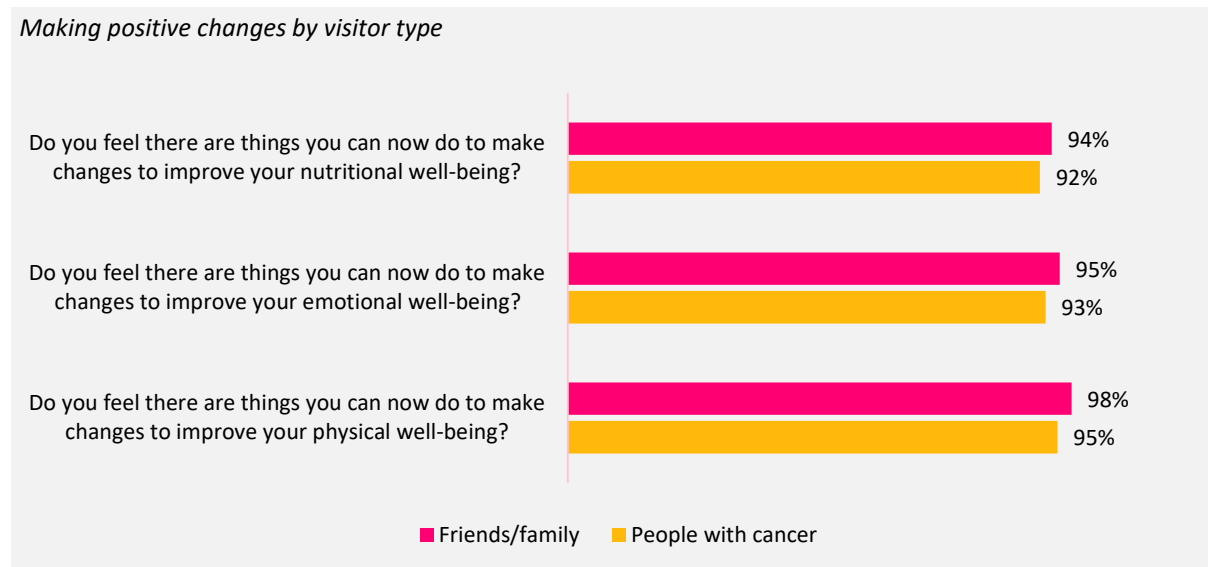
Whilst we see the level of engagement from mostly “strongly agree” to “agree” from *Believes action is important* to *Maintains changes, even under stress*, the responses remain more than 85% positive. This is also true across all centres.

77% of all attendees feel prehab has improved their health engagement



Overall, 77% have said prehab has had a positive impact on their health engagement. This is lower in some centres, however 80% of those who responded “a little” or “not at all” already had a high level of engagement with their health.

Over 90% of those who attended feel they can now make positive changes to their physical activity, emotional well-being, and diet/nutrition



This is lower in those who attended online, where between 77% and 91% of attendees said they could make positive changes going forward.

Of those who gave a reason for responding with “no” to being able to make positive changes to their nutritional, physical, or emotional wellbeing, many stated it was due to them already being engaged and making positive choices in these areas.

A deeper dive into the delivery and quality of the Prehab programme via semi-structured interviews was conducted with four individuals and this is outlined in more detail under “Post-prehab Impact” on page 16.

Coming back to Maggie’s

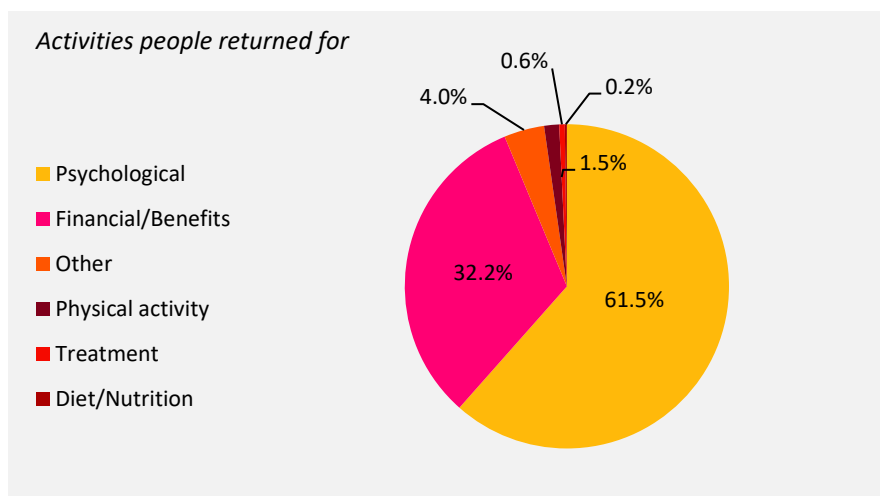
Across the Maggie’s prehab programme in Scotland, PIDs have been recorded for 61% of all those who have attended.

41% of those with a PID have returned, with an average delay of 29 days from Prehab to people returning to Maggie’s.

We have aggregated the programmes people have accessed into:

- Emotional support
- Physical activity
- Nutritional advice
- Financial/legal advice
- Understanding treatment
- Other

62% come back for emotional support



Emotional support includes seeing a psychologist, and taking part in a workshop or support group. 32% come back to seek financial/legal advice, and 6% of return visits being for a physical activity, nutritional advice, and for a course about treatment, or another activity.

Post-prehab Impact

A follow-up survey and invitations to interviews were sent to those who provided their email address for further communication.

Seven people completed the survey, and four people took part in an interview.

These have helped us to better understand their experience of prehab, and how it has impacted them six weeks or more after the session.

People felt comfortable coming into Maggie's, however an icebreaker would help those not comfortable speaking in a group setting

While our visitors experienced a warm welcome, not all were aware it would be a group setting. As a result, some found opening up more difficult than others, and felt that a few minutes getting to know each other may have helped, especially for those who attend on their own.

"There were seven guys there, five of them had their wives, it was just me and another guy who were on our own. There's some of the things they were talking about you know, it was a bit embarrassing for me,"

– DUN-0220

People have a continued awareness of their emotional well-being, nutrition, and physical activity

Attendees have been able to take the tools learned in prehab to help their recovery during or post-treatment

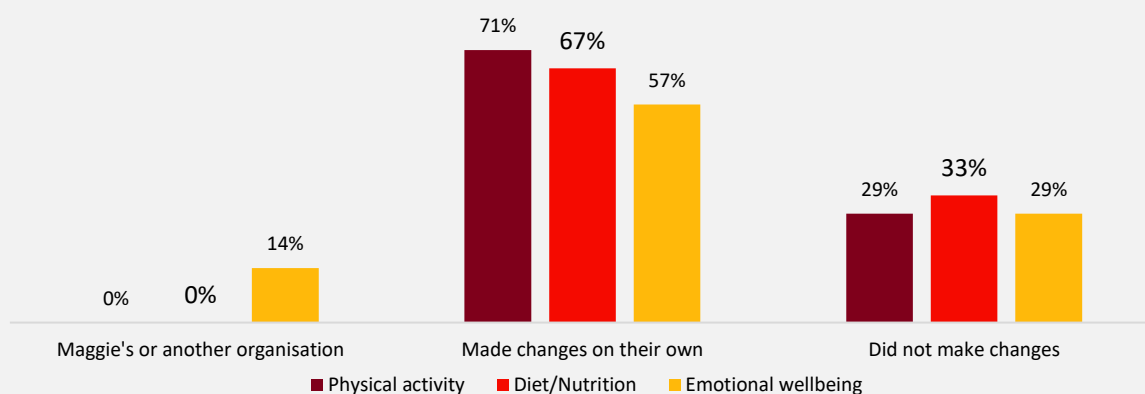
“...all those little targets that we made about keeping healthy, taking care of yourself. That's ongoing now. You know, I haven't put that on the shelf, that is a part and parcel of my life”

- HIG-0048

“And I've been doing some batch cooking... I've made some Scotch broth, you know, in portion sizes for the freezer. You know just so it's something to hand that you know you're not having to stop and think”

- ABE-0022

Methods visitors have used to make positive changes



Most people have been able to make positive changes using their own resources, however some have struggled to make changes due to pre-existing health conditions or the side effects from treatment or surgery.

“The biggest problem I'm having is the incontinence, that is really debilitating. Just can't do very much, you know? I didn't think it'd be that bad”

- DUN-0220

Some services are an essential part of recovery, such as provision of incontinence pads post-prostatectomy. However, breakdowns in these services can cause a barrier to someone making healthy choices. So, making sure we provide more specific contact information for these services would enable people to better manage their side effects, and make the healthy changes.

People feel in control of their health

A cancer diagnosis and subsequent treatment can cause people to feel helpless, and as if treatment is something being done to them. The knowledge and skills learned in prehab enables people to feel more in control over their health.

“Enabled, really, I think this the word, I felt more enabled, more empowered, more in control. You know, can we ever be in control of life, but I just felt that I was more of a co-worker in what was going on rather than just, you know, in space?”

- HIG-0048

References

1. Public Health Scotland:
<https://publichealthscotland.scot/publications/cancer-incidence-in-scotland/cancer-incidence-in-scotland-to-december-2020/data-files/>
2. Scottish 2011 Census:
<https://www.scotlandscensus.gov.uk/census-results/at-a-glance/ethnicity/#:~:text=91.8%25%20of%20people%20identified%20as,Traveller%20or%20'White%3A%20Other>

Appendix 3 - Story and feedback

A man with oesophageal cancer attended prehab. He had been diagnosed, but not yet started treatment (chemotherapy followed by surgery).

During prehab, he was pleased to receive reliable information from Maggie's, and found the handouts useful to refer to. He also felt welcomed and encouraged to come back to Maggie's for advice in the future.

He has since been back to Maggie's multiple times, and his daughters have been with him on a number of occasions. His conversations with Maggie's staff "have covered a lot of prehab after prehab."

Coming up to his surgery, he has been able to use prehab to prepare:

"So that's when I revisited [mind mapping]. You think, you know, I'm going for an operation here, what do I need to look at specifically for my operation? I need to keep my fitness up. I need my mindset right"

He is glad prehab took place at Maggie's, as he doesn't think he would have received the follow-up care and support anywhere else.

"I think if it was run by the hospital, we would have done the [course], and then that would have been it, I don't think it would have the same follow-up or the backup"

Of prehab at Maggie's and the continuing support he has received, he says:

"...it's quite strange how well prehab fits with Maggie's... if you look at the main aspects that come out of the prehab course in particular, every single one of your learning outcomes is something that's taught, or supported, or part of the main Maggie's ethos, in a way. It's in your curriculum. It's naturally there"

Hospital staff have seen the benefit of not only the prehab session, but also having it at Maggie's

When interviewed, a Bowel Cancer CNS in the Aberdeen Oncology team echoed the sentiments of our storyteller by saying she had been encouraging people to make healthy life changes but had limited resources with which to do so.

She said hosting prehab at Maggie's is an appropriate setting for patients, partly due to the proximity to the hospital, also because of the peer support in having others with similar experiences to speak with.

She said that referring to Maggie's is very easy and takes very little time, and those who have been to our prehab session have very positive feedback; they feel very supported, both by Maggie's and

their peers, and find the practical information useful. In themselves they seem more positive and have goals to focus on before surgery.

In terms of other information that would have been useful, she mentioned letting her know the people referred who did and did not attend, so perhaps a feedback mechanism could be looked into, to enable NHS colleagues to plug the gap on their side for anyone missing out on prehab.