



Macmillan Northern Ireland Prehab Programme Evaluation

Interim evaluation summary and key findings

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M·E·L Research would like to thank the Clinical Project Managers for all their help in delivering this evaluation so far. Additional thanks go to the Health and Social Care Trusts, Councils, the Public Health Agency, the Department of Health, prehab delivery staff and patients who provided feedback on their experiences.



Introduction

- M·E·L Research was commissioned in February 2023 to carry out an evaluation of the prehab programme.
- The aim is to provide:
 - NI-wide and Trust-specific learning for the prehab programme and project-level development
 - evidence of effectiveness of universal and targeted prehabilitation and implementation strategies
- The plan is to conclude the evaluation by March 2025.
- This interim report focuses on the key findings from the process evaluation phase which aims to gather and share important learning of the programme implementation to-date and observes any likely impact on people living with cancer, on delivery staff/partners and on the wider system

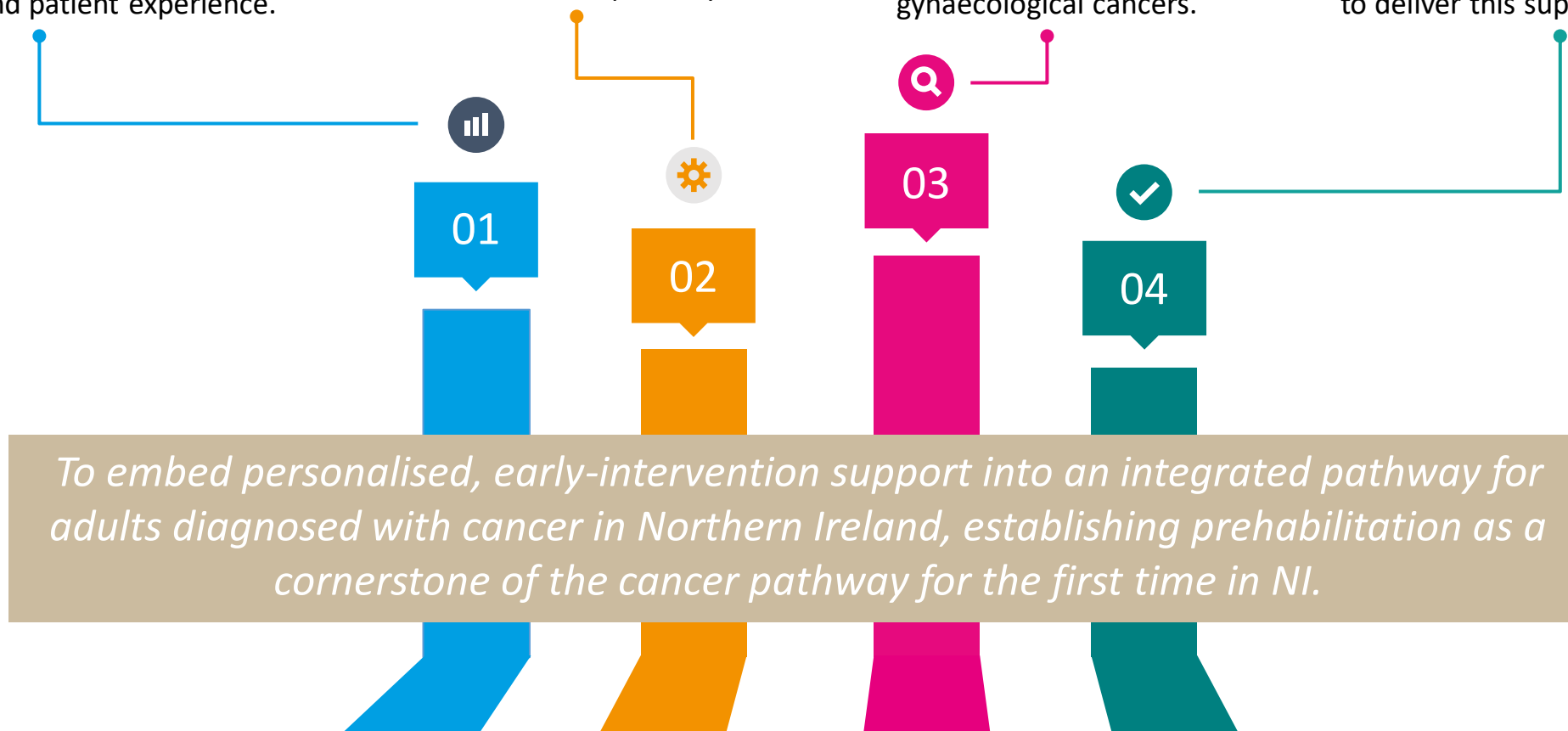
Aim and goals of the Programme

Support 3,000 people living with cancer across NI through the provision of personalised, early-intervention prehabilitation, and a further 13,500 people affected by cancer, transforming both outcomes of treatment and patient experience.

Establish a model of equitable access to this support for colorectal cancer patients across NI, ensuring equity of access through the integration of standards across all pathways.

Develop prototypes for the delivery of this support for up to five further tumour groups (two in each trust) - lung, upper Gastrointestinal and Hepatobiliary, head and neck, breast, and gynaecological cancers.

Demonstrate evidence of impact on patient outcomes, patient experience, and cost-benefit to support a business case with recommendations for future investment such as commissioning to deliver this support sustainably.



Programme implementation (1)

South Eastern

Prehab progress: Operating since Mar 2021
PM in post: Since Sept 2022
Tumour sites involved: Colorectal, lung, head & neck

Western

Prehab progress: Piloted between May-Nov 2023 with the colorectal team; restarted in Feb 2024
PM in post: Since Oct 2022
Tumour sites involved: Colorectal

Belfast

Prehab progress: Started in late 2023 but soon paused due to PM post becoming vacant; aiming to restart in Jun 2024
PM in post: Jun-Dec 2022
Tumour sites involved: Colorectal, moving to focusing on rectal cancer

Nothern

Prehab progress: Operating since Nov 2022
PM in post: Since Oct 2022
Tumour sites involved: Colorectal, lung, haematology, endoscopy pilot

Southern

Prehab progress: Operating since Nov 2023
PM in post: Since May 2023
Tumour sites involved: Colorectal, lung

Programme implementation (2)

- Over 1,000 patients have been referred to the Programme across the five Health and Social Care Trusts (HSCTs) from the beginning of the Programme (different date in each HSCT) and end of May 2024. The table on the right provides a breakdown of the number by HSCT and by tumour site.
- 600 patients were referred to the Macmillan Move More Programme for prehab support between January 2022 and February 2024 – accounted for 17% of the total referrals including rehab. The table on the right indicates the number of patients supported for prehab in each District Council.

HSCT	Colorectal	Lung	Head & Neck	Haematology	Total
Northern	219	224		11	454
Southern	41	26			67
South Eastern	305	74	123		502
Western	36				36
Belfast					No data
Total	601	324	123	11	1,059

Source: Prehab Clinical Project Managers

Council	HSCT supported	Total number of beneficiaries supported	Of these, how many were: prehab	Of these, how many were: non-prehab
Belfast	Belfast	420	44	376
Causeway coast and Glens	Northern, Western	272	47	225
Ards and North Down	South Eastern	450	147	306
Fermanagh and Omagh	Western	350	48	302
Armagh, Banbridge & Craigavon	Southern	400	60	340
Mid-Ulster	Northern, Southern	312	38	274
Derry and Strabane	Western	340	20	320
Antrim	Northern	441	52	389
Lisburn and Castlereagh	South Eastern	232	101	131
Mid and East Antrim	Northern	144	12	132
Newry, Mourne and Down	Southern, South Eastern	154	31	123
Total		3,515	600	2,918

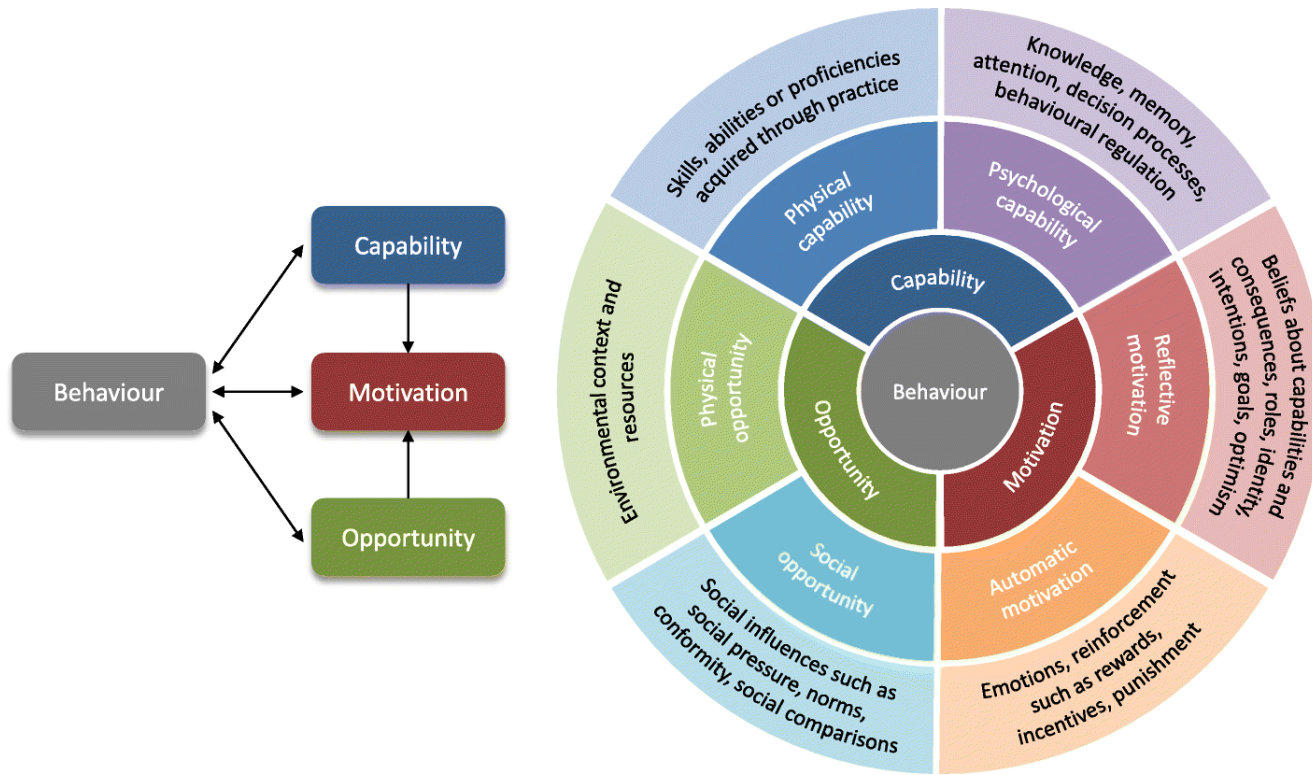
Source: Macmillan

What have we been trying to find out?

The evaluation is guided by the key objective to understand the impact and outcomes of the Prehab Programme on people living with cancer, on service delivery staff/partners and on the wider system. The table below outlines the core research questions that we try to answer through patient and stakeholder engagement and analysing of programme related data.

Evaluation aim	Key research questions
<p>What are the impact and outcomes for people living with cancer?</p>	<ul style="list-style-type: none"> ▪ Do people living with cancer have timely and equitable access to prehabilitation? ▪ How effective is the prehabilitation programme in terms of supporting family and friends of people living with cancer to adopt a healthier lifestyle? ▪ What does good quality holistic care planning look like for people living with cancer? ▪ What are the impacts prehabilitation has on outcomes for people living with cancer?
<p>What are the impact and outcomes for staff?</p>	<ul style="list-style-type: none"> ▪ How does information sharing happen, between and within local areas / partner organisations? ▪ What training and support is provided to those delivering the prehabilitation programme? ▪ What training and support is provided to other key partners or staff? ▪ How does the confidence and ability to signpost people living with cancer affect the experience of staff?
<p>What are the impact and outcomes for the wider system?</p>	<ul style="list-style-type: none"> ▪ What is required to make an effective, sustainable prehabilitation programme in NI? ▪ How would success be defined by different partners?

Behaviour change model



The evaluation team also incorporated behaviour change theory, the COM-B model, into the design of patient survey, discussion guides to help identify **capability**, **opportunity** and **motivational** factors impacting on people's perceived ability to adopt a long-term healthier lifestyle – a key outcome of the prehab programme.

What has happened so far?

Evaluation design

- Evidence and document review
- Scoping discussions
- Theory of Change and evaluation framework
- Evaluation design workshop
- Internal review on ethics and safeguarding
- F2F meeting with Clinical Project Managers to design the data collection template

Primary data collection

- Patient survey x 60
- Patient interview x 8
- Stakeholder interview x 39

Empty survey packs, including an M·E·L freepost envelope, were prepared by M·E·L Research and the surveys have been distributed from January 2024 by the Clinical Project Managers. Patients who have been referred to prehab since January 2023 and have had at least a 3-month gap since diagnosis are invited to take part in the survey. No personal information is exchanged between the Trusts and M·E·L. Patients who wish to take part in any follow-up research activities related to this evaluation can indicate so in the survey and provide their contact details. The Project Managers will continue to send out the surveys as and when appropriate until December 2024.



Collation and analysis of programme outputs

- Monthly referral data report by Clinical Project Managers
- Move More Programme data provided by Macmillan

Other activities

- Presenting and attending relevant steering group meetings

Patient outcome data



The data was collected by MMCs and provided by South Eastern Trust, covering 254 patients.

EQ-5D-5L

- The EQ-5D-5L questionnaire asks patients to self-assess their health state over five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has 5 levels: no problems, slight problems, moderate problems, severe problems and extreme problems/unable to.
- EQ visual analogue scale (EQ VAS) is normally utilised alongside ED-5D-5L. It asks patients to rate how good or bad their health is TODAY on a scale of 0 to 100.
- Assessments were taken at three time points: right after diagnosis, end of prehab before treatment and at 4-month follow-up

Under each heading, please tick the ONE box that best describes your health **TODAY**

MOBILITY

I have no problems in walking about

I have slight problems in walking about

I have moderate problems in walking about

I have severe problems in walking about

I am unable to walk about

SELF-CARE

I have no problems washing or dressing myself

I have slight problems washing or dressing myself

I have moderate problems washing or dressing myself

I have severe problems washing or dressing myself

I am unable to wash or dress myself

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

I have no problems doing my usual activities

I have slight problems doing my usual activities

I have moderate problems doing my usual activities

I have severe problems doing my usual activities

I am unable to do my usual activities

PAIN/DISCOMFORT

I have no pain or discomfort

I have slight pain or discomfort

I have moderate pain or discomfort

I have severe pain or discomfort

I have extreme pain or discomfort

ANXIETY/DEPRESSION

I am not anxious or depressed

I am slightly anxious or depressed

I am moderately anxious or depressed

I am severely anxious or depressed

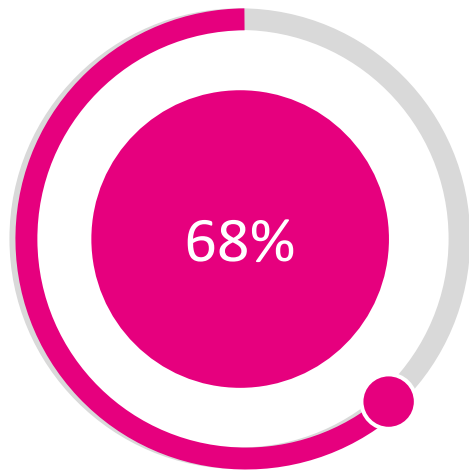
I am extremely anxious or depressed

Noticeable improvements can be observed at the end of prehab across most dimensions, in particular around anxiety/depression.

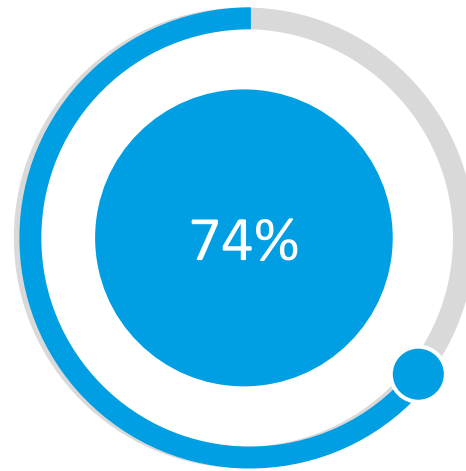
		No problems	Slight problems	Moderate problems	Severe problems	Unable	No/slight problem
Mobility	Baseline (n=254)	59%	20%	16%	5%	0%	79%
	End of prehab (n=129)	65%	20%	12%	2%	1%	85%
	4mth follow up (n=149)	53%	26%	14%	6%	1%	79%
Pain Distress	Baseline (n=254)	39%	34%	21%	6%	0%	72%
	End of prehab (n=129)	34%	42%	19%	5%	0%	76%
	4mth follow up (n=148)	32%	44%	19%	5%	0%	76%
Self Care	Baseline (n=254)	39%	34%	21%	6%	0%	72%
	End of prehab (n=129)	34%	42%	19%	5%	0%	76%
	4mth follow up (n=149)	32%	44%	19%	5%	0%	76%
Usual Activities	Baseline (n=253)	63%	24%	10%	2%	1%	87%
	End of prehab (n=128)	62%	27%	7%	4%	0%	89%
	4mth follow up (n=148)	51%	26%	16%	5%	2%	78%
Anxiety Depression	Baseline (n=251)	36%	29%	27%	8%	0%	65%
	End of prehab (n=129)	40%	37%	16%	5%	2%	78%*
	4mth follow up (n=147)	50%	30%	16%	5%	0%	80%*

*statistically different at 95% confidence level

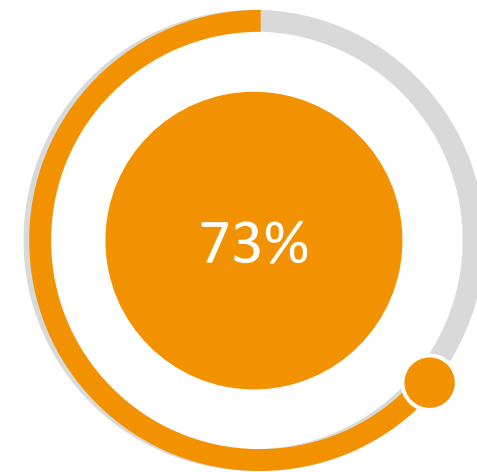
There was a significant increase in self-reported overall health status at the end of prehab before treatment, compared to the baseline. A longer-term effect can also be observed at the 4-month follow-up point. (EQ VAS)



Baseline
(n=257)



End of prehab
(n=132)



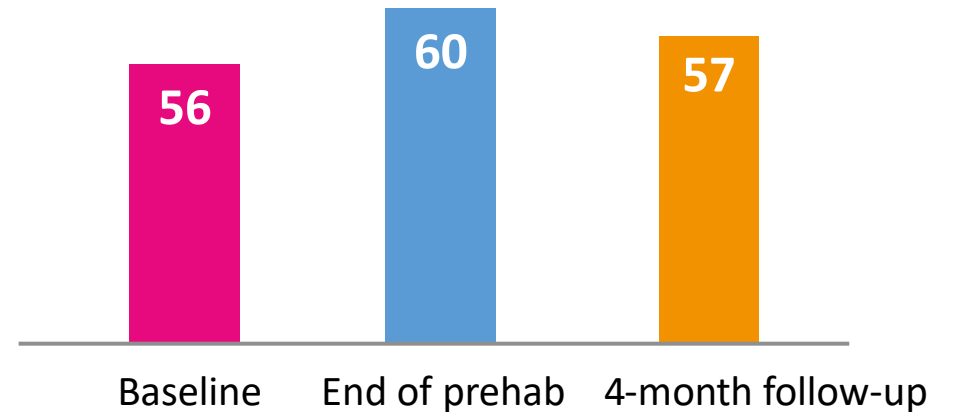
4-month follow-up
(n=151)

Self-efficacy For Exercise (SEE) Scale

How confident are you right now that you could exercise three times per week for 20 minutes if:

	Not Confident					Very Confident					
1. The weather was bothering you	0	1	2	3	4	5	6	7	8	9	10
2. You were bored by the program or activity	0	1	2	3	4	5	6	7	8	9	10
3. You felt pain when exercising	0	1	2	3	4	5	6	7	8	9	10
4. You had to exercise alone	0	1	2	3	4	5	6	7	8	9	10
5. You did not enjoy it	0	1	2	3	4	5	6	7	8	9	10
6. You were too busy with other activities	0	1	2	3	4	5	6	7	8	9	10
7. You felt tired	0	1	2	3	4	5	6	7	8	9	10
8. You felt stressed	0	1	2	3	4	5	6	7	8	9	10
9. You felt depressed	0	1	2	3	4	5	6	7	8	9	10

- Total score is calculated by summing the responses to each question. This scale has a range of total scores from 0-90. A higher score indicates higher self-efficacy for exercise.
- Assessments were taken at three time points: right after diagnosis, end of prehab before treatment and at 4-month follow-up
- The SEE score increased significantly from 56 at baseline to 60 at the end of prehab, before treatment.

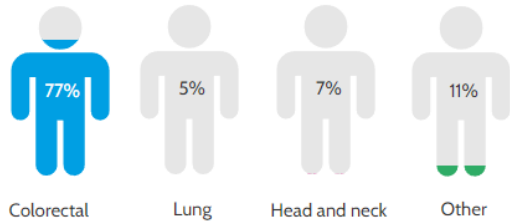


Key findings from patient engagement

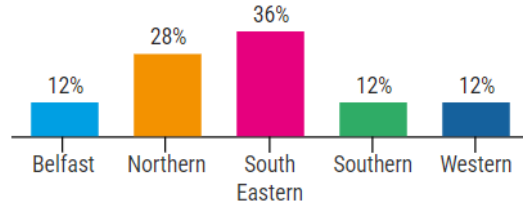


Patient survey - respondent profile

Cancer type

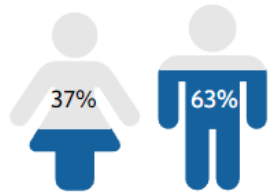


Received diagnosis and treatment at

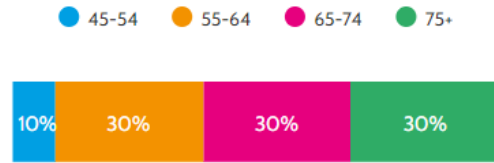


Gender

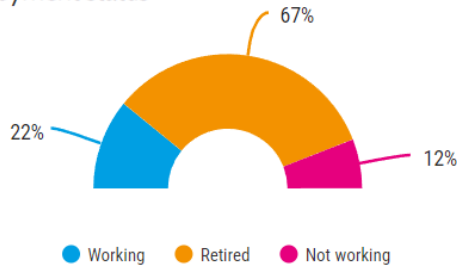
1 respondent self-identified as non-binary



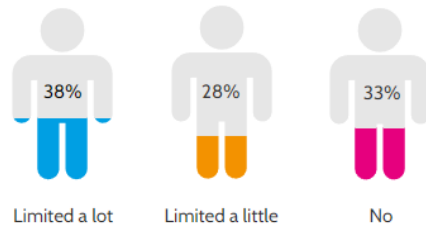
Age group



Employment status



Limited by a health problem or disability



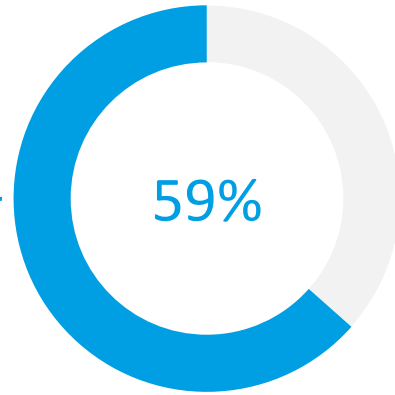
Source: prehab patient survey

- 324 survey packs have been sent out so far with 60 returns, representing a 19% response rate. Of the 60 returns, 30 patients agreed to take part in either a follow-up interview or an online community which will take place later in the summer.
- 8 respondents have been interviewed so far and most were by a Macmillan Peer Facilitator.
- More survey participants have been treated at either Northern or South Eastern Trusts which are expected as prehab has been implemented for longer in those Trusts and therefore have a bigger patient cohort. It is also anticipated that the majority of the participants have been treated for colorectal or bowel cancer as this is the first tumour site to implement prehab across all Trusts. 11% of the participants reported to have been treated for more than one type of cancer.
- Please note that the percentages you see in the charts in this report may not always add up to 100% due to rounding issues.
- The following slides present the key findings from the patient survey and interviews. Please note that sub-group analysis has not been carried out due to the small sample base.

Most respondents felt that prehab was offered to them at the right time, and the information provided was easy to understand.

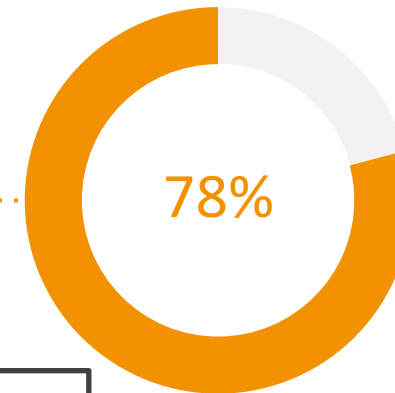
When was prehab offered?

- Around the time of diagnosis or just a few days after: 59%
- A few weeks after diagnosis: 26%
- Can't remember: 15%



Was prehab offered at the right time?

- Just right: 78%
- Too early: 10%
- Too late: 12%

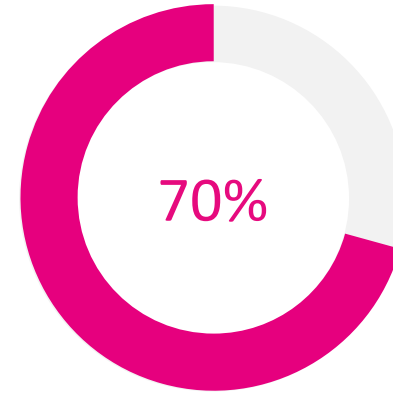
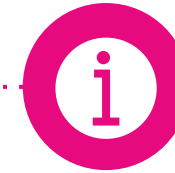


Reasons for feeling:

- ❖ Too early: lots to take in, lots of appointments to attend, feeling information overload
- ❖ Too late: contacted a week or so before surgery

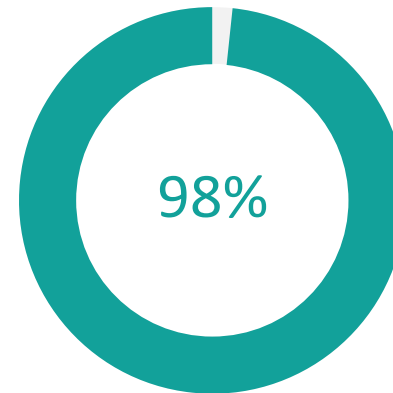
Provided with written and verbal information?

- Both info: 70%
- Written info only: 7%
- Verbal info only: 16%
- None provided: 7%



Information easy to understand?

- Very or fairly easy: 98%
- Not easy at all: 2%



Most patients understood what prehab meant when it was first offered to them, however not everyone felt that they were able to ‘take the information in’ at the time or had enough time before surgery to take part.

“Perhaps it should be explained more the benefit, when just diagnosed. It is a lot to take in and although you want the best outcome, surviving is the most important.” – Male, 55-64, Head and neck

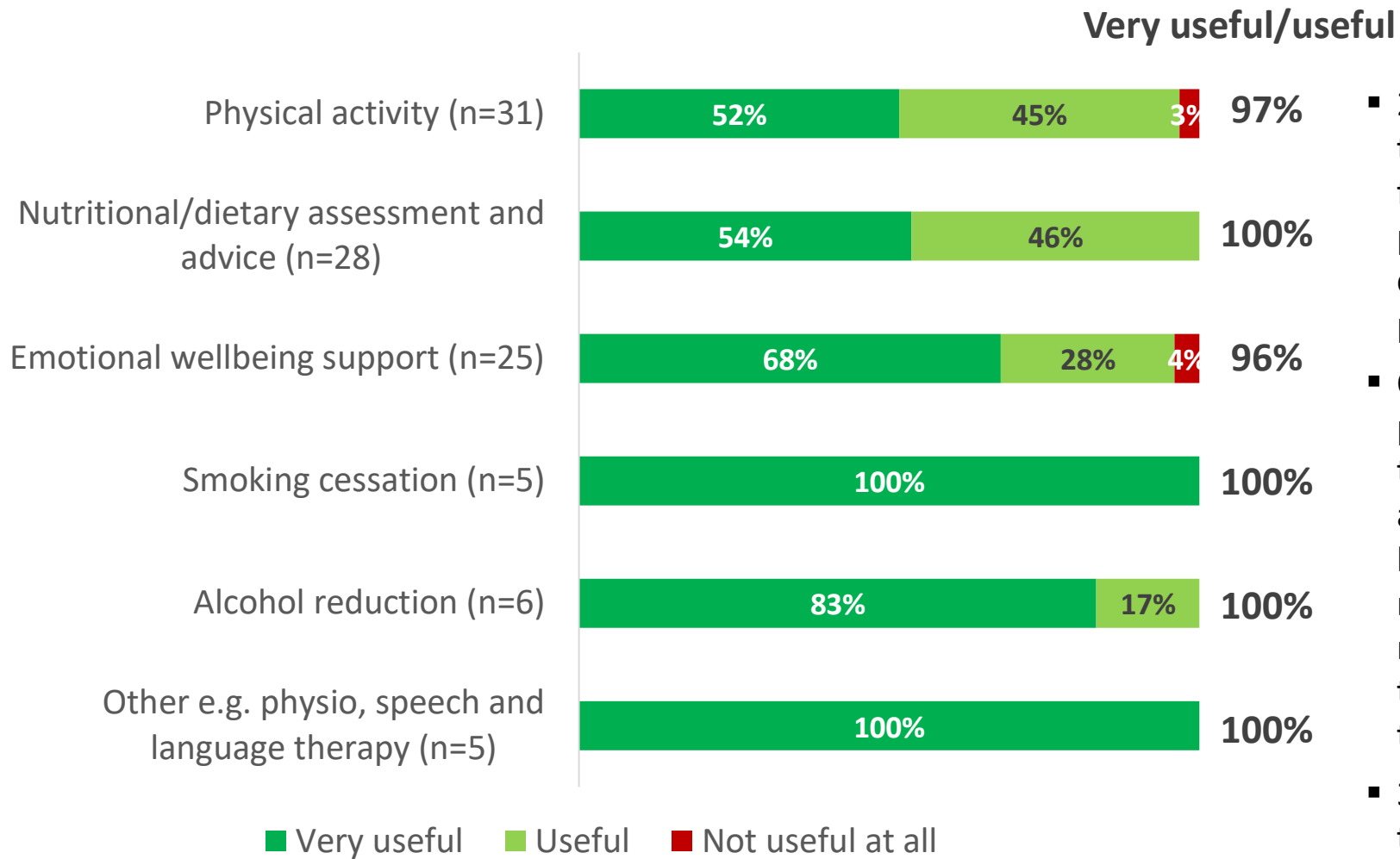
“I received a call from a girl at the local leisure centre 1 week prior to my surgery. I am not sure that I took in what she was saying.” – Female, 75+, Colorectal

“By limiting information and almost drip feeding rather than giving all info at once. Everything was very fast.” – Male, 65-74, Colorectal

“I did not receive any sessions, just a phone call but it was close to my surgery, and I was very distracted.” – Female, 75+, Colorectal



Almost everyone who were supported by prehab found the interventions useful



- 21 out of the 60 respondents (35%) said that they participated in the Prehab Programme fully and another 15 (25%) said that they participated partially. It's clear to see from the chart that almost all those who took part in prehab have found the support useful.
- Of the 15 respondents (25%) who did not take part, 4 of those said that there was too little time between diagnosis and treatment; another 4 indicated that other health issues have prevented them from taking part or mentally they were not ready for it; 3 other respondents said they weren't able to get to the leisure centre, and another 2 suggested that they didn't need the support.
- 3 respondents couldn't remember whether they participated in the Prehab Programme or not.

Source: prehab patient survey

Positive experience of prehab and personalised care was evident from patient feedback. Patients felt they were consulted and given a choice.

"Felt that I was managed very well and felt involved and able to manage the plan myself." – Male, 55-64, Colorectal

"The trainer asked about the type of surgery I was having and took me through several apparatus at the gym that would be beneficial for my legs and abdomen." – Female, 55-64, Colorectal

"I had a speech and language therapist from an early stage, everyone was always letting me know what was going to happen." – Male, 55-64, Head and neck

"Yes very much so and if I wasn't interested in some parts, that was okay." – Male, 65-74, Colorectal

Most respondents agreed that prehab helped them better prepare for their treatment. More noticeable impact of prehab includes improving people's physically activity level and their ability to take care of their mental health and wellbeing.

77%

agreed that prehab helped them better prepare for their surgery/treatment.

(n=35)

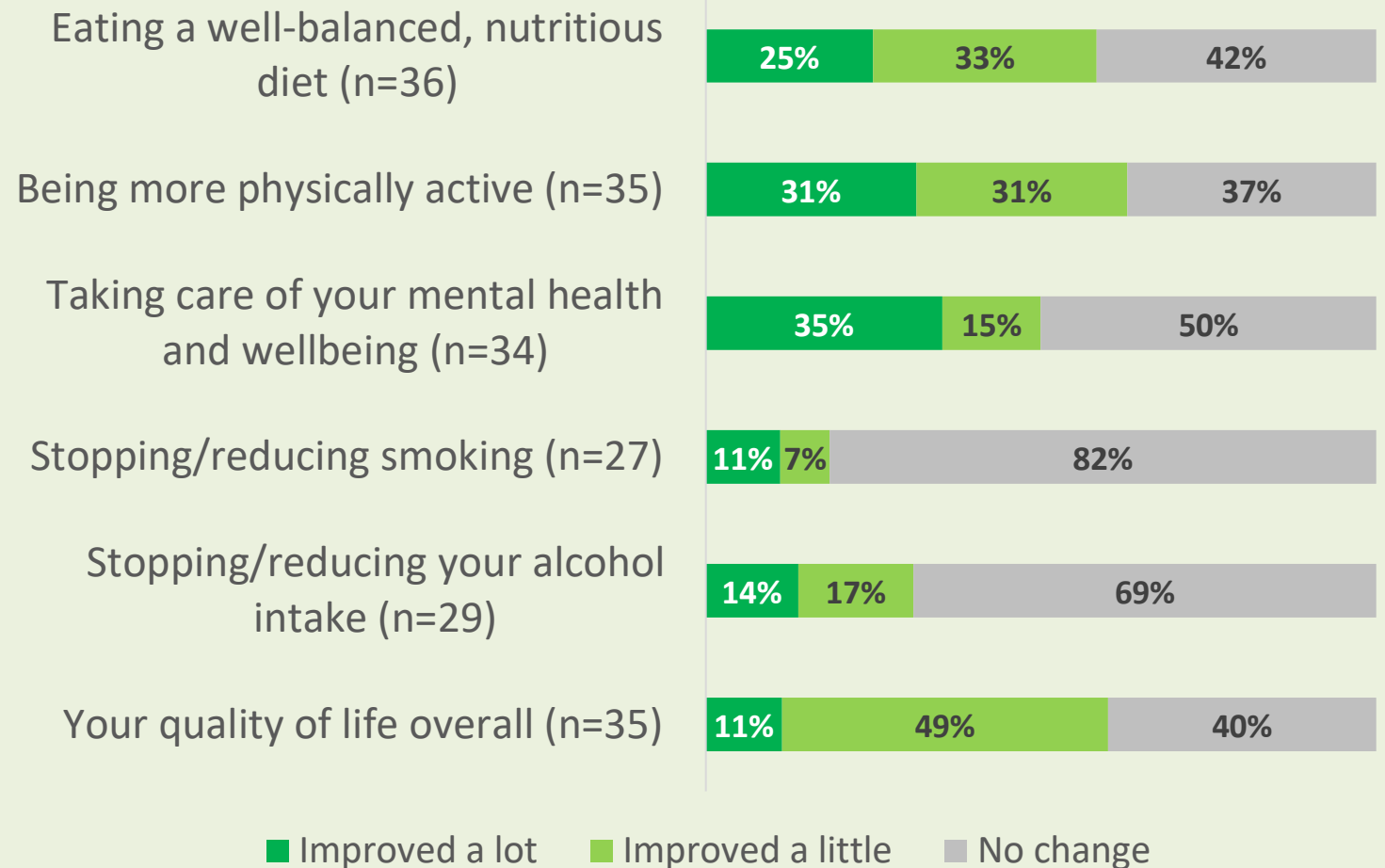
66%

agreed that prehab helped improve their recovery time after surgery/treatment.

(n=35)



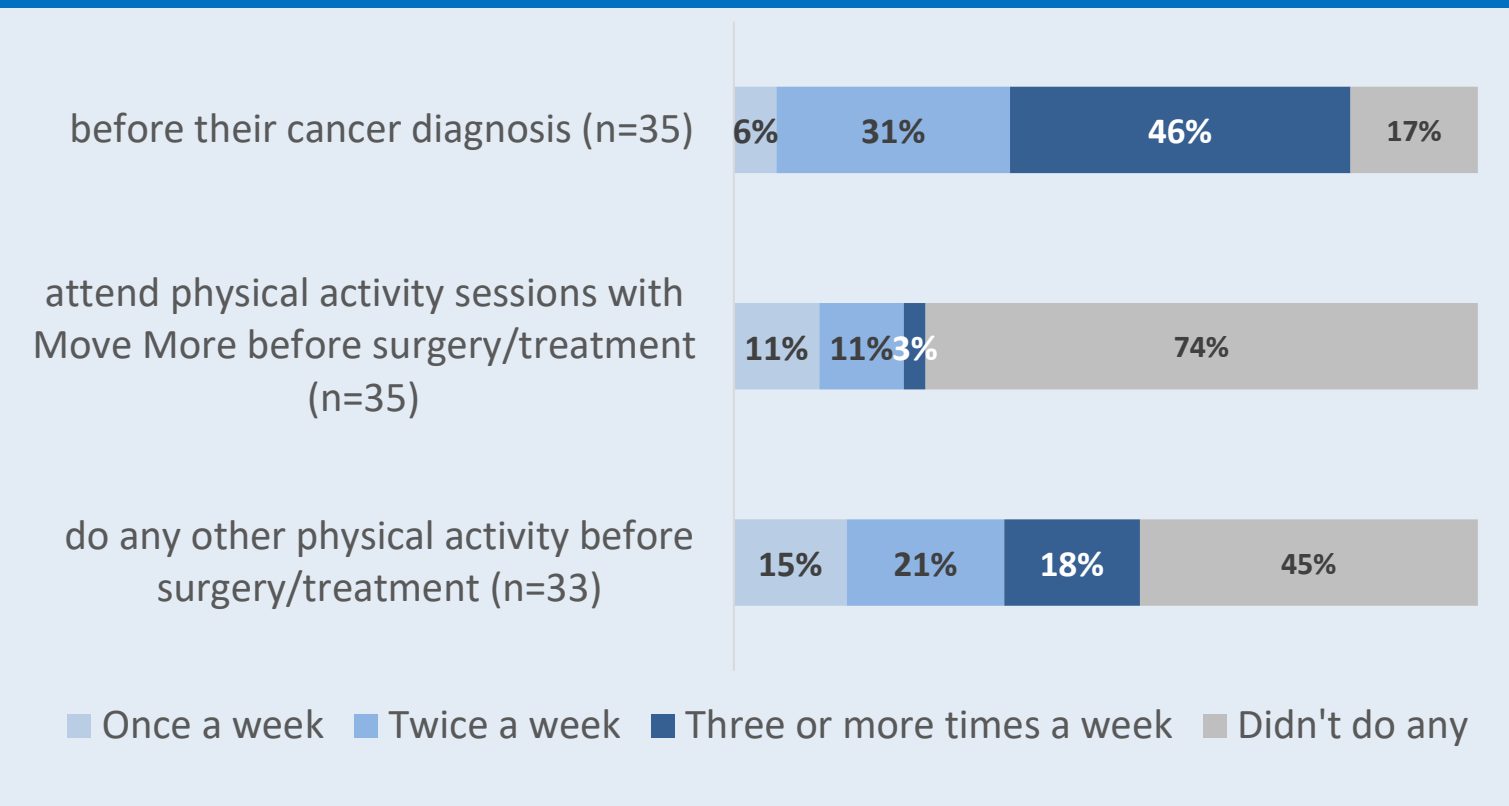
What has improved as a direct result of the prehab programme?



Source: prehab patient survey

Over a third have increased their physical activity level since prehab; the majority would maintain or increase that moving forward

How often did people do physical activity?



61% continued to be physically active before surgery/treatment whether it was supported by a MMC or by themselves

37% said the amount of physical activity they have done since receiving prehab has either increased a lot or a little

39% have done or intended to do more physical activity moving forward; another 33% have done or intended to continue at the same level

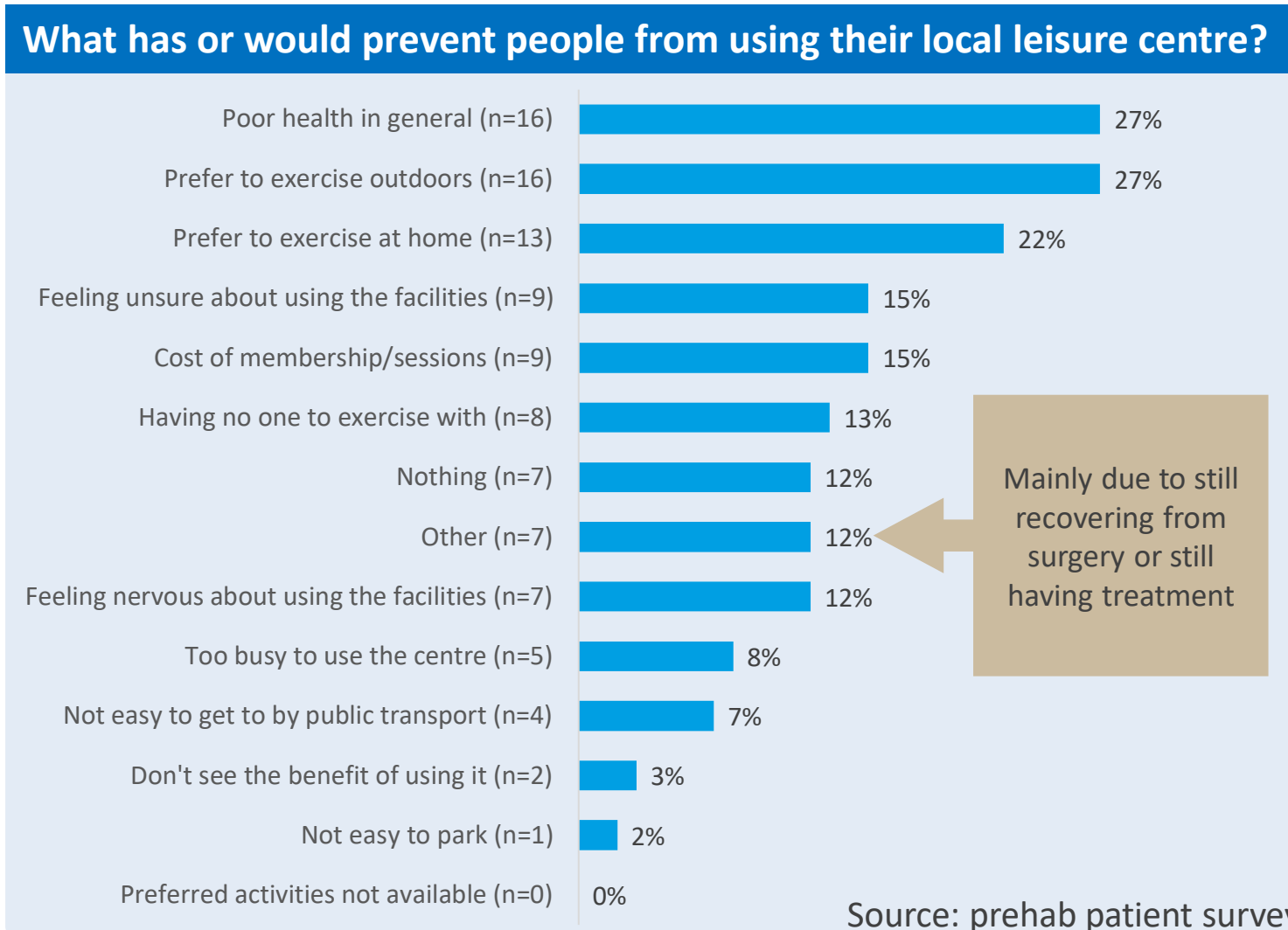


Prehab has to an extent encouraged continued usage of local leisure centre, although poor health has been highlighted as main barrier and a noticeable proportion preferred to exercise outdoors or at home.

23%
 have continued
 to use their
 local leisure
 centre since
 diagnosis
 (n=60)



62%
 said the prehab
 programme has
 encouraged this
 (n=13)





The benefits and positive impact of prehab were clearly felt by those who received support.

“Big impact, great confidence in the programme and the services delivered, this also gave my family confidence in my treatment and any questions they knew who to contact.” – Male, 55-64, Head and neck

“Helped me immensely as focused on what I needed to get me through surgery and to have a good recovery.” – Male, 55-64, Colorectal

“I do feel supported and felt that the introduction of all parts of prehab early gave me options.” – Male, 65-74, Colorectal

“I felt that I got all the support I needed from Prehab trainer, Macmillan staff, to all the hospital staff. There is nothing I can find to criticise.” – Male, 65-74, Colorectal

“The prehab service had not been formally commenced when my nurse asked if I'd like to take part. Despite this my prehab worker was fabulous, knowledgeable, kind. I'd like to see this support available to everyone.” – Male, 55-64, Colorectal

“I received brilliant support eg: stopping smoking, and pre-op gym membership & instruction & fitness. And I knew that other supports were easily available if I wished.” – Male, 55-64, Colorectal

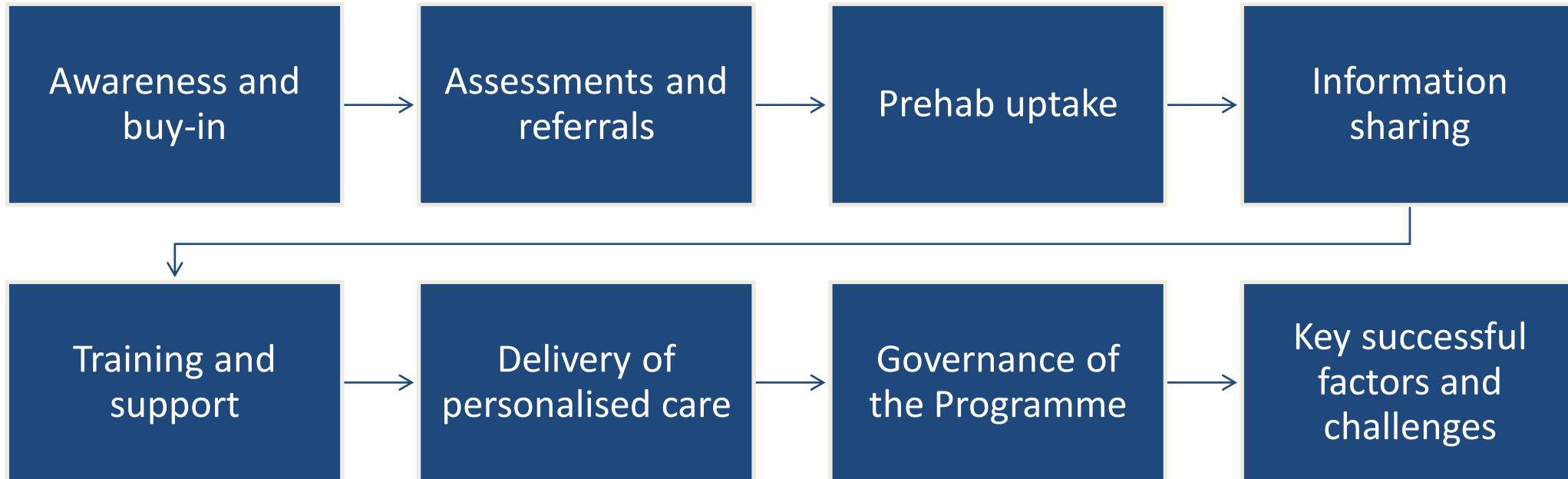
“My surgery happened soon after I was introduced to the programme and I was unable to be involved in the activities. I found the support I did receive was helpful + encouraging for now and in the future.” – Female, 75+, Colorectal

“I received all the best help anyone could ask for, 5.”
- Male, 55-64, Colorectal*



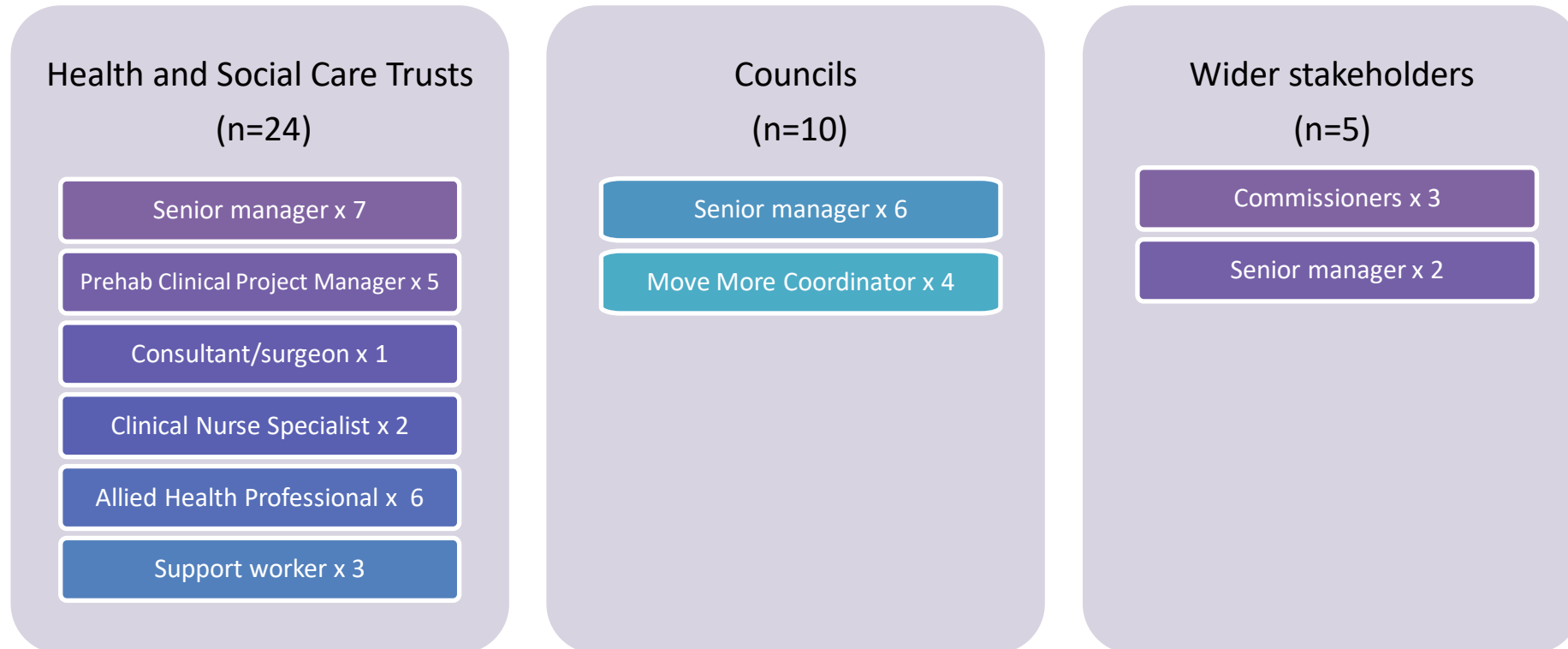
Key findings from stakeholder engagement

The next section of the report will discuss some main learning points of the Programme implementation to-date, referring to some key elements from awareness and buy-in to the governance of the Programme (see image below), based on feedback from professional stakeholders.



Whom have we spoken to so far?

- 39 professional stakeholders have been engaged either via an 1-2-1 or a paired interview between December 2023 and May 2024. These included:



- We will recontact stakeholders later this year to map out the outcomes and impact of the Programme; we will also aim to engage with more consultants and CNSs.



Awareness and buy-in

There is willingness and commitment to deliver prehab between partner organisations, but a lack of sustainable funding/secured resources has made it challenging to implement.

- Senior management within HSCTs tended to agree that there is a good level of buy-in within their organisation, especially within the multi-disciplinary teams (MDTs). Councils we have engaged so far have also had support from elective members who saw it as an important intervention to support local residents diagnosed with cancer.
- From delivery staff's perspective, endorsement and support from senior management, not only at the strategic level but also at the operational level, can really empower and help them better deliver the Programme. It was also felt that prehab should be promoted more within the Trusts beyond the prehab teams.
- The key challenge so far has been the **lack of funding and secured resources**. It has been signified by stakeholders across HSCTs the need for dedicated Clinical Nurse Specialist (CNS) and Allied Health Professional (AHP) resources which are difficult to secure without appropriate funding as most are under resourced already. Most have been providing support on goodwill and it is not sustainable. Some HSCTs have reported not able to secure or no longer having AHP support for prehab. The Move More Coordinator (MMC) role have also been highlighted as an integral and crucial part of the Programme delivery, however not all Councils are able to continue to deliver a role dedicated to cancer interventions without external fundings.

“There's definitely buy-in, but what we've all realised is it takes time.” – Senior manager, HSCT

“The buy in is very much there and everybody knows there is a great MDT working and supporting the prehab programme.” – Senior manager, HSCT

“Our councillors in terms of our elected members and management are very supportive of the programme and that is evident in terms of the sustainability of the [MMC] post.....Council greatly values the Macmillan Move More Programme as a whole.” – Senior Manager, Council

“Our elected members were very supportive of the programme. It's very emotive and they're keen to get involved.” – Senior Manager, Council

“There's been no additional funding, so any additional work has to be within people's existing roles and responsibilities which makes it more difficult. Need more infrastructure.” – Senior manager, HSCT

“When you haven't got the AHP resource and support secured, it's really hard to get prehab going.” – Wider stakeholder

“The Trust doesn't have any colorectal CNS input and Dietetic input and limited oncology.....The biggest challenge has been to test and develop pathways when we don't have any dedicated staff.” – Senior manager, HSCT

“...we're happy to do it, but we need to be mindful that ultimately, we're there to provide a broad range of services and everything that we provide is heavily subsidised.....can be difficult to try and maintain a lot of services if we're not sourcing other funding streams.” – Senior manager, Council

Assessments and referrals



Having weekly MDT involving consultants and CNSs to identify patients suitable for prehab has worked well; it becomes more challenging if there is limited input from CNSs to assess and refer. Not having enough time between diagnosis and first treatment has been the main barrier to deliver the benefits of prehab for patients.

- The MDT was considered an ideal forum for all relevant healthcare professionals to jointly agree which patients are suitable for prehab. Effective flow of information and patient follow-ups can be observed where prehab delivery staff were involved in the MDT.
- Key challenges identified are:
 - **Limited CNS resource to identify and assess patients for prehab:** CNSs have been pivotal in kicking off the referral process. Without inputs from them, the referral numbers are hard to pick up.
 - **A lack of physical space or an appropriate location:** Some stakeholders have highlighted the difficulties of finding an appropriate room or location for the prehab clinics. Some have had to run the clinic in two different locations.
 - **Insufficient time between diagnosis and first treatment:** Most stakeholders have highlighted this issue, particularly amongst colorectal patients. It was viewed as a very positive outcome that patients were being treated so quickly, however it has made it harder to deliver an effective prehab intervention and has also generated 'unproductive' referrals.
 - **Inconsistent approach to assessments at the Council level:** There was some confusion around what type of assessments MMCs were required to carry out and the frequency, which meant that there was not a consistent approach across the 11 Councils. The need to assess patients also meant more admin time for MMCs to administer relevant tests and log outcomes. A consensus was achieved during the meeting held between M·E·L's Evaluation Lead and the five Clinical Project Managers in December 2023 that there is sufficient evidence to demonstrate the outcomes of prehab for patients, and therefore it would be more beneficial for the Programme if the MMCs' efforts were focused on delivering the intervention without needing to carry out any assessments.
 - **A lack of pre-engagement with patients :** Not all patients referred to MMC have received information about prehab or necessary equipment for exercising at home. This can make it harder for MMCs to get buy-in and engagement from patients from the outset. Hospital delivery staff have also found it harder to get patients onboard if they have not been told about prehab by their consultant or CNS.

“Referral process generally works well but is 'bitty' in nature with lots of follow-up calls and trying to fit appointments in within short timeframes.” – Delivery staff, HSCT

“This pathway was very good because it meant at the MDM all the key medical people involved in the patient care were around the table, so they all knew who was going to be appropriate to go to the prehab.” – Delivery staff, HSCT

“We don't have the same level of input from the CNS as [they are] very understaffed at the moment...we're having to go ourselves to pick these patients up” – Delivery staff, HSCT

“I think we could do far more if we got them even two or three weeks earlier” – Delivery staff, HSCT

“They'll be called for their surgery or will be called for their chemo radiotherapy just before we can get that two week period” – Delivery staff, HSCT

“I think the time scale is the big problem..... Their (i.e. patients') time is probably very restricted with appointments, meeting times, calls, you know, so they just can't drop everything to attend [prehab].” – MMC, Council

“I don't know if any other coordinators might have found it, but as I said, it was just more the fact that there wasn't that clarity there that who should have been collecting what and when.” – MMC, Council



Prehab uptake

Patient engagement and uptake seems to be better where CNSs are more involved, and when patients have more time between diagnosis and treatment. Once accepted the prehab referral, most patients are receptive to the support provided.

- It was commonly noted between hospital delivery staff that more awareness and engagement at the consultant level would significantly help improve patient buy-in to prehab.
- Even when surgery or treatment was imminent, some patients were still receptive to the advice given to help improve their physical condition, however there could be a disconnect between receiving advice and actually implementing it.
- Educating family members that it is okay and good for their loved ones to be physically active while waiting for their treatment was considered as important as educating the patients themselves.
- Many stakeholders highlighted the importance of patients wanting to take ownership of their health as it is deemed a key determinant on their willingness to take part in prehab.
- MMCs reported that patients who were male or already led an active lifestyle before their diagnosis were generally less likely to engage with prehab. Those whose surgery was imminent were also more reluctant to attend group sessions at the leisure centre, reasons being, e.g. not considering it a priority comparing to attending hospital appointments, wanting to stay healthy by keeping away from a busy environment.

"Generally, most people are open to it and really keen on it and try to really engage in it...there are others that don't want to get involved, that report that they've a lot going on in their lives. They have a lot of appointments at that time as well, for their PET scans, for their CTs, for their biopsies, all the different things that's going on. They find it difficult to take on something else." – Delivery staff, HSCT

"What I've seen is that the family members are often more anxious than the patients. So I think it's been really good in that sense to give the relatives evidence of what the patient could achieve with exercise before they start the treatment." – Delivery staff, HSCT

"With people living longer and cancer incidence on the increase, we do need to empower people to take more control over their health so that they're not always expecting the medical people to click their fingers. And I think prehab is a big wake up call for people to realise it's not all about medicines and operations. Actually, that part of the jigsaw puzzle is lifestyle. So I think it's a very innovative yet essential way for the health service to look forward to the delivery of service in the coming years." – Delivery staff, HSCT

"Patients can be aware of the benefits and know that that's something they should do, but it's actually getting them to change their lifestyle is more a bit of a challenge." – Delivery staff, HSCT

"I think if the consultants probably 'sold it' more, you could better buy in from patients, but I do totally understand that the consultant has so many other things that he has to concern himself with at that point in time" – Delivery staff, HSCT

"A lot of patients have never heard of it before...maybe if the doctors could briefly tell them what it is or point them in the right direction...a lot of the time they're not really aware of the benefits. They kind of think 'oh, I'm eating OK' or whatever." – Delivery staff, HSCT

Information sharing



The current approaches are fit for purpose; however, the updating process is manual and can be time consuming.

- Encrypted email has been the main method used to share prehab patient information, whether it is within the HSCTs or between HSCTs and Councils. The approach works fine when the communication is one-way, but several stakeholders also highlighted the inefficiency and inconvenience when needing to update different partners with progress. It has been suggested that a central digital platform where relevant staff could access and update patient information/progress would work well.
- The level of information shared has not been consistent across organisations and many have felt that having more details beyond name, address, phone number, and treatment plan etc. would help them better prepare and support patients – information around comorbidities were often mentioned.



Training and support

Staff training has largely been informal and internally delivered. Some felt unsure about how best to engage patients when they have just been diagnosed with cancer or felt a lack of cancer specific knowledge/understanding of comorbidities.

- Prehab was a new area for most delivery staff. It was felt that there should have been more opportunities for training and induction as opposed to 'picking things up' as they go along. This in turn has had an impact on some staff's confidence in being able to support patients through prehab.
- Some suggested having a shared resource or literature around the prehab service specification and expectations, common FAQs to help problem solve, and how to adjust advice for patients with different comorbidities would be helpful.
- Staff also welcomed the opportunity to network and learn from others, e.g. having a prehab AHP forum.
- MMCs are used to working with rehab clients who have been through treatments and are trying to live well with cancer. Prehab clients on the contrary have just been told that they have cancer; there are lots of emotions and things that are more of a priority for them to sort. It was suggested that training around how best to engage this client group and what's appropriate and not appropriate to say would have been helpful.

Delivery of personalised care



Personalised care is evident in prehab delivery and a core strength of the programme. Standardisation and a consistent approach will be required to ensure the equity of the service across Northern Ireland.

- Stakeholders across the board firmly believed and endorsed the holistic and personalised care approach to prehab. Advice and support they ‘prescribed’ are tailored to individual needs. Linking up prehab support with personal motivations has helped with behaviour change. Patient feedback echoes this finding.
- There was a strong desire to have a regional and consistent approach to deliver the Programme which also calls for having clear expectations / goals set for each delivery partner and having more regular regional steering group meetings to set standards and hold people to account.

"I think they need to find it within themselves to be motivated. I think they can only do that if the risks versus benefits are explained to them properly" – Delivery staff, HSCT

"A lot of them used the word 'accountability'..... They were coming up with great tips themselves - like one man wanted to drink less coffee. He said he couldn't give it up, so he said 'you know what I could do? I could drink it in a smaller cup'. It was amazing." – Delivery staff, HSCT

"It's listening to what matters to them first and foremost..... empower somebody to actually take control of their health and well-being. And our job is to empower that long-term with Move More." – MMC, Council

"It is thinking outside the box and just trying to tailor it to very much specific to that patient.....if you can find the right thing for the patient and the right level, then hopefully they'll take that on board to be able to carry it out and feel like they're achieving and that will lead to a more positive experience for them." – Delivery staff, HSCT

"One of the things that we were very good at was buddying people up who had maybe been through the same sort of experience, you know, and that could have been done by just inviting a couple of people to the gym at the same session." – MMC, Council



Governance of the Programme

Delivery staff felt that the local steering group meetings can be informative and help improve partnership working. Senior managers suggested that more clarity is needed for the regional steering group meetings.

- **Regional steering group:** Although the membership has been limited to senior management within the five HSCTs and 11 Councils, it was felt that the group still consisted of too many people which could lead to difficulties in decision-making. There was a strong desire to have regular meetings and for which clear objectives/key performance indicators are set for the remainder of the Prehab Programme and members' roles and responsibilities are clearly defined. Some senior managers from HSCTs also felt that some of the Trust representatives were too remote from the delivery of prehab to be able to effectively contribute to the steering group.
- **Local steering group:** the local steering groups have also not been held consistently across the five HSCTs, due to reasons such as uncertainties over the continuation of the Move More Programme after March 2024. Where it did happen on a regular basis, stakeholders involved felt a greater sense of partnership working.

"The [local] steering meeting is really good and the structure is very clear in terms of who falls under the Prehab team and then at what point then they would come back to our core services so that there's continuity of care and support that the patients need kind of throughout their journey, which has worked well.....I find the steering group is really well organised and yeah, really impressed with how it's run and how informative and how much information that we can get from that kind of short meetings." – Senior manager, HSCT

"I think the advisory group before has been really useful because there's been, you know, the likes of ourselves and the Council managers and the prehab project managers and they're really, really getting into the nitty gritty of what are the issues and challenges and barriers and to be able to look at some of that stuff." – Senior manager, HSCT

"I'm not quite sure the purpose of the regional meeting I've attended. I think 2 out of the three, I'm not sure of its focus or its remit.....Not sure after 2 years what are the milestones and what has been accomplished with it." – Senior manager, HSCT

"At that level they are not close to the detail and don't have a full understanding of what's actually happening either, so sometimes you need a wee bit of both. You need to have senior people but like the people that are leading it and are close to the detail of it to have a really better understanding of some of the issues." – Senior manager, HSCT

"I don't know if I really understand why there's prehab and rehab steering group meetings and sometimes it's hard to know what levels are attending which.....the last couple of meetings I've been at there hasn't been much of an update." – Senior manager, Council

Key successful factors and challenges



Key enablers to Programme implementation

- Getting AHPs involved and securing relevant resources, e.g. admin, support workers, on the outset
- Having MMCs in post across all 11 Councils, ready to support the Programme
- A strong believe that this is the right thing to do has motivated staff to ‘get stuck in’ even though without extra funding or resource. The willingness to continue to deliver prehab and to do it well is shared across partners.
- Positive and productive working relationships between HSCTs and Councils; MMCs who have had a longer history of working with HSCTs through the rehab element of the Move More Programme have found it much easier to continue or expand the relationship for prehab. Having regular local steering group meetings has also helped reinforce that.



“The fact that we've got the additional AHP support and even band 4s to work alongside because the band 7 AHPs are very quickly coming to a point of saturation where they're almost unable to take on much more.....We have to remember that not everything within Prehab needs to be delivered by a band 7, so it's that aspect of skill mix. What aspects of this can be delivered by someone else within your team and even coming back to the CNS, is there anything that the support worker for the CNSs can be doing that will enable them to do their part that is needed?” – Senior manager, HSCT

“I think from a cancer prehab this is a really good example of how community planning can work successfully where we've had the community and voluntary sector that we signpost to. We have our Councils and our Trusts working in partnership and I think this is one of the successes of community planning.”– Senior manager, HSCT

“What I would say is they're vitally, vitally valuable services and 90% of our delivery model is based on Move More Coordinators' support.” – Delivery staff, HSCT

Key challenges to Programme implementation (1)

- **A lack of dedicated resource/funding:**
 - As mentioned before in this report, not being able to secure the additional crucial resources required for the Programme within HSCTs, i.e. CNSs, AHPs, admin support, etc. has proven to be a major challenge for most. A lot of support the Clinical Project Managers managed to draw upon was based on people's goodwill and it is not sustainable.
 - Uncertainties over the funding of the Move More Programme in late 2023/early 2024 also added to the challenge. Some Councils have managed to sustain their MMC post on a short-term basis without external funding, and some have had to incorporate cancer support into other wider services. Senior managers were concerned the valuable skills the MMCs have could be easily lost if future funding (both internally and externally) cannot be secured.

"It's only in hindsight that you look back and you sort of think it's made their, you know, the Project Manager's jobs that much more difficult when there's no other additional staff available to link in to deliver the programme." – Senior manager, HSCT

"So I think for us everyone, psychology, physio, the AHPs, health improvement colleagues and cancer services colleagues have all given their time and their expertise on top of everything else, but that only can be sustained for so long." – Senior manager, HSCT

"There's such a variance in terms of AHP and cancer staff available across all of the Trusts, and that's become more apparent through this prehab programme as well." – Senior Manager, HSCT

"Goodwill runs out and people are engaged with these things when it's a pilot, but when the pilot comes to an end and still no funding is available, then services say that we can't continue to do this on top of our day job." – Delivery staff, HSCT

"You can't have a programme unless you've got the people on the ground that are delivering it. They are the most important part of this programme, you know, so if they're not there, there isn't the programme." – Senior manager, Council

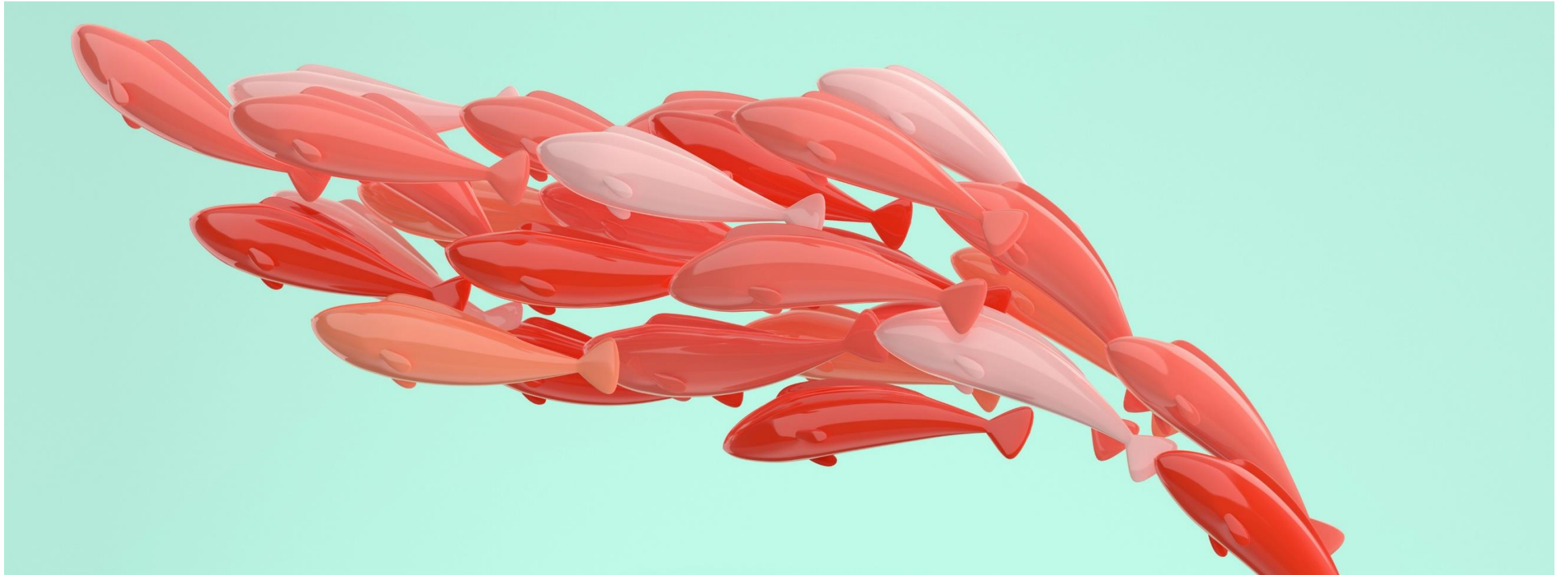
Key challenges to Programme implementation (2)

- **Recruitment and the start of relevant key posts were not aligned:**
 - The recruitment of the five Clinical Project Managers took a significant amount of time mainly due to the lengthy process of agreeing and finalising the job description and advertising the role within each HSCT; the individuals were in post between September 2022 and June 2023. Meanwhile, MMCs were already in post and had been funded since April 2021 to deliver prehab. Most of the Clinical Project Managers needed to develop a prehab service within their Trust from scratch which took time and resource. This meant that some only started prehab officially towards the end of 2023.
 - The Macmillan Regional Pathway Integration Lead role was designed to work with the HSCTs and Councils to develop a regional approach to prehab. The post started in March 2023 but became vacant again after 7 months – not enough time to make significant progress.

Key challenges to Programme implementation (3)

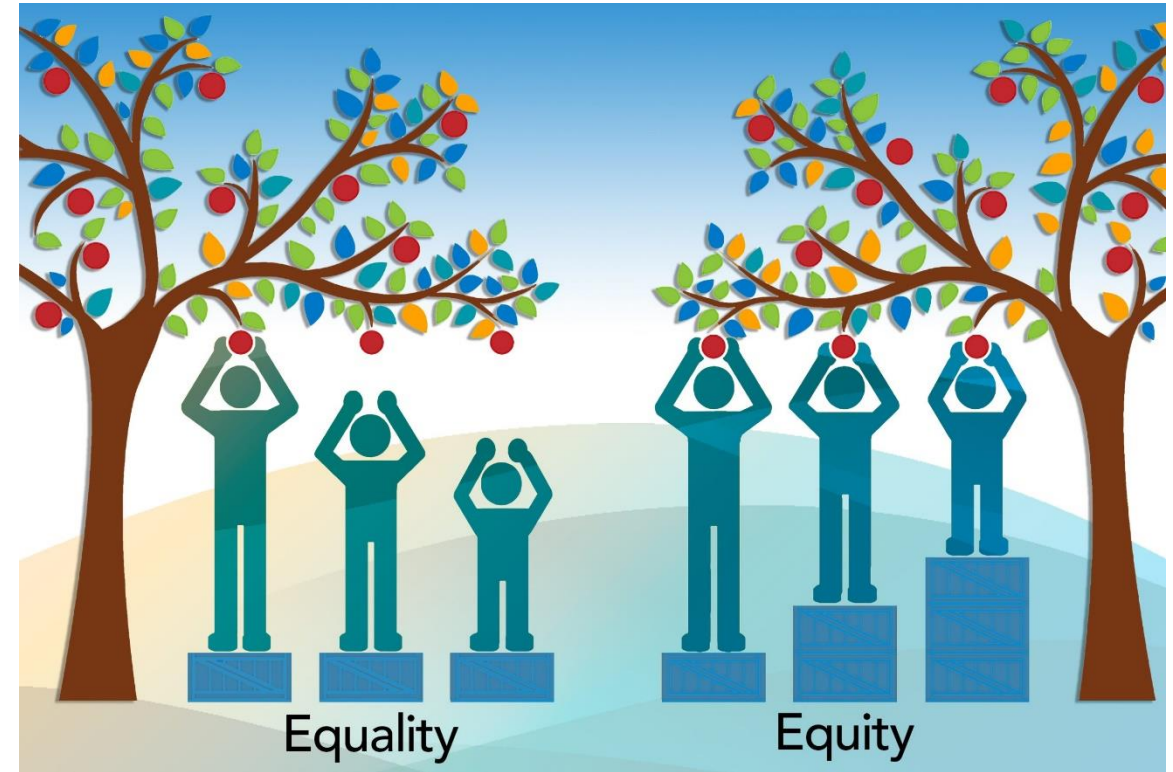
- Leading from prehab being implemented at different timing in each HSCT, the Councils have felt that the **inconsistent and low referral numbers** have made it harder for them to justify and argue the need for dedicated resources for cancer prehab.
- **Not having enough time between diagnosis and starting treatment**, especially amongst colorectal patients, has also been highlighted as a main challenge for delivering an effective intervention. Based on historical data provided by the Northern Trust, 28% of colorectal patients were not deemed suitable for prehab due to their treatment starting within two weeks.
- Due to the **lack of a regional approach**, the HSCTs and the Councils do not have a standardised pathway to deliver prehab. Patients can receive different level of support depending where they live and in which Trust they receive treatment.
- Overall, it was felt that there has been a **lack of strategic vision and long-term planning** for the Programme, with unclear operational goals.

Recommended actions for the remainder of the Programme



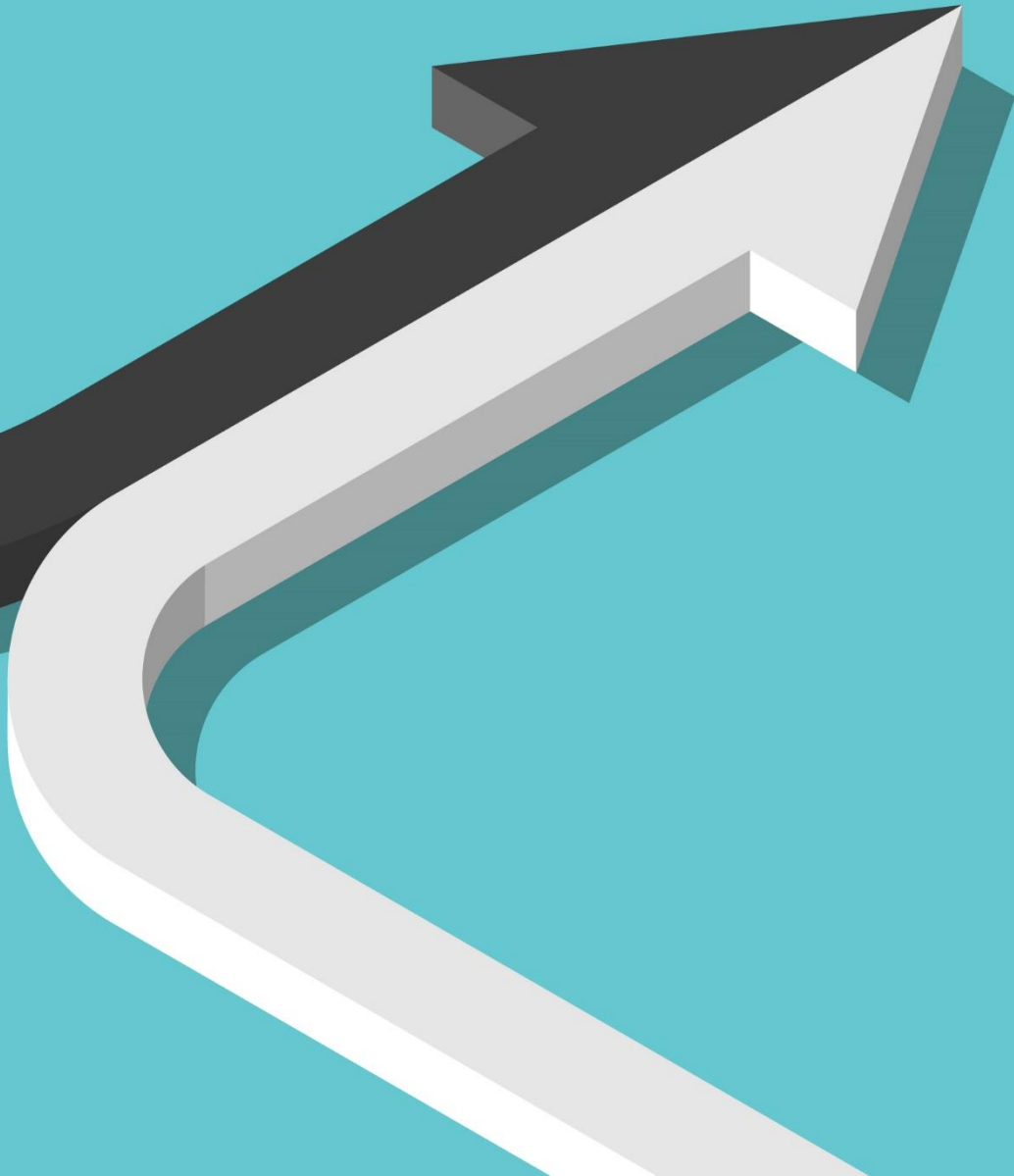
Develop a regional approach with clear goals and aspirations

- To have a consistent offer and to provide an equitable prehab service for people newly diagnosed with cancer across NI is a crucial next step; this was also emphasised by the Department of Health. The newly appointed Macmillan Regional Pathway Integration Lead will play a pivotal role in facilitating this.
- Goals, targets and each HSCT's implementation plan should be clearly communicated to help each partner see how they can help contribute to those; progress and challenges should also be regularly tracked and reported to the regional steering group meetings to problem solve and improve performance.
- It might be worth considering reviewing the membership of the different levels of steering group and reconfirming the focus for each.



Review the Move More referral criteria to maximise the impact of every single referral

- There have been question marks over whether the colorectal patient cohort can benefit the most from prehab due to a high ratio of patients having a very short waiting time to surgery. As a result, MMCs have encountered a higher refusal rate and have not been able to deliver the intervention but instead giving advice and using the opportunity to plant the seed for rehab. It was argued whether these patients need to be referred to MMCs in the first place.
- Concerns were raised over MMCs' and Council's capacity to be able to support the Programme if prehab is to be implemented in more tumour sites.
- During the next few months while most Councils are still trying to feel their way around how best to support prehab, it might be a good opportunity for key stakeholders from all HSCTs and Councils to work together to map out and agree the referral criteria so that the approach is consistent across the board.



Start to think about the sustainability of the Programme and to have an exit strategy

- HSCTs will need to start mapping out their longer-term plan for prehab. The Clinical Project Manager role has been considered pivotal in delivering the Programme; with the first Manager finishing in January 2025, plans need to be in place soon to sustain the role/functions.
- It has been demonstrated that prehab cannot be delivered effectively without additional and dedicated resource. Where and what are the opportunities to seek funding? At what level can prehab be sustained if extra funding cannot be secured or provided?
- It is widely agreed that the sustainability of Move More is crucial to prehab service delivery however concerns have also been raised over the sustainability of the rehab element which accounts for 83% of the Move More clients. It has been argued that Move More should be treated as one cohesive programme supporting people living with cancer.





This project has been delivered to ISO 9001:2015, 20252:2019 and 27001:2013 standards.

