

Designing, developing, and funding personalised cancer prehabilitation and rehabilitation

A How to Guide

PRosPer (Prehabilitation, Rehabilitation and Personalised Care) project funded by Health Education England and produced by Macmillan Cancer Support



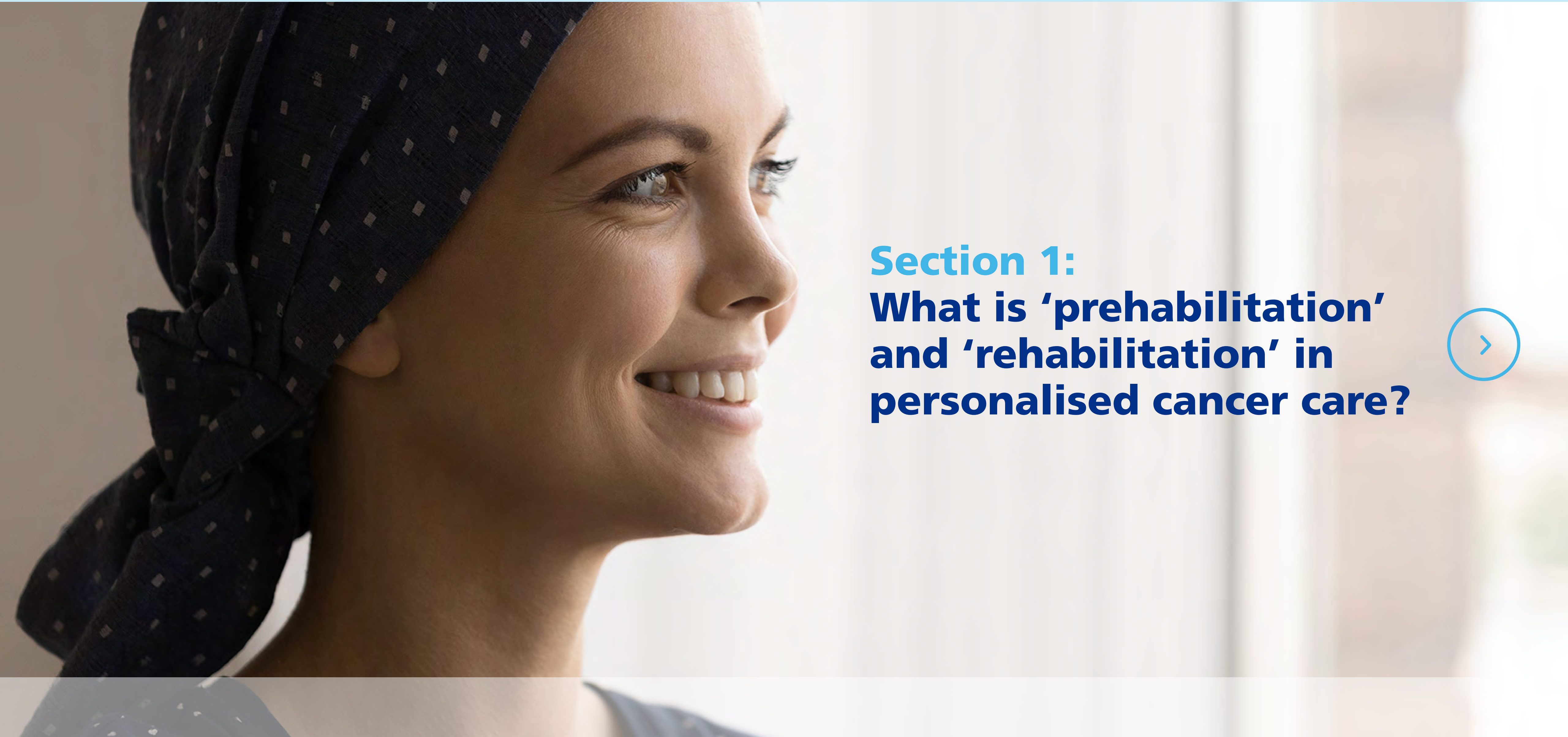


Planning funding for cancer patients and pathways

An interactive guide

- Thank you for looking at this guide. It showcases examples of projects running across the cancer pathway, including before, during, and after treatment.
- To support all users, the information is interactive, using case studies across the different regions of the United Kingdom, with different project outcomes.
- You may be looking at this as lead for an organisation, or as a health professional, considering the implementation of projects to support people at different stages of the cancer pathway. Please choose the most appropriate case studies, or section of the guide, for your scope of practice.
- You can take as little or as much time as you wish to engage in the content.
- Examples of business cases provide some data on cancer prevalence, [Index of Mortality Deprivation \(IMD\)](#), and health inequalities. This data will not be updated regularly, and you may find that more recent data in your geographical area may better support your case for funding.

Section 1: **What is 'prehabilitation'** **and 'rehabilitation' in** **personalised cancer care?**



Section 1: What is 'prehabilitation' and 'rehabilitation' in personalised cancer care?



Prehabilitation



Prehabilitation, as a component of rehabilitation, should underpin the whole cancer pathway and is an approach we seek for all people with cancer through co-developing a personalised prehabilitation care plan (PPCP) as part of their overall care plan. Prehabilitation can optimise cancer treatment by promoting health and wellbeing as part of a continuum of preventative, restorative, supportive and palliative rehabilitation interventions. Prehabilitation, specifically including exercise, nutrition and psychological support, should be integral to the care of all those with cancer diagnosis.



Rehabilitation



Rehabilitation aims to restore, as far as possible, a person's roles and functions whether they are affected by physical or mental ill health and help them to adjust to limitations where required. Cancer rehabilitation is relevant at all stages of the cancer pathway from diagnosis and treatment planning (prehabilitation), through cancer treatment, in the recovery phase after treatment and in palliative or end-of-life care. Rehabilitation is a central element of cancer care. It enables patients to make the most of their lives by maximising the negative consequences of treatment and symptoms.



Personalised care

Personalised care aims to support people with cancer to make decisions about their care through identification of their concerns and goal setting facilitated by professionals. By making care personalised, individuals have greater choice and control over the way their care is planned and delivered. This approach will ensure that the care and support they receive is based on what matters to them, their individual strengths and needs.



Prehabilitation and Rehabilitation



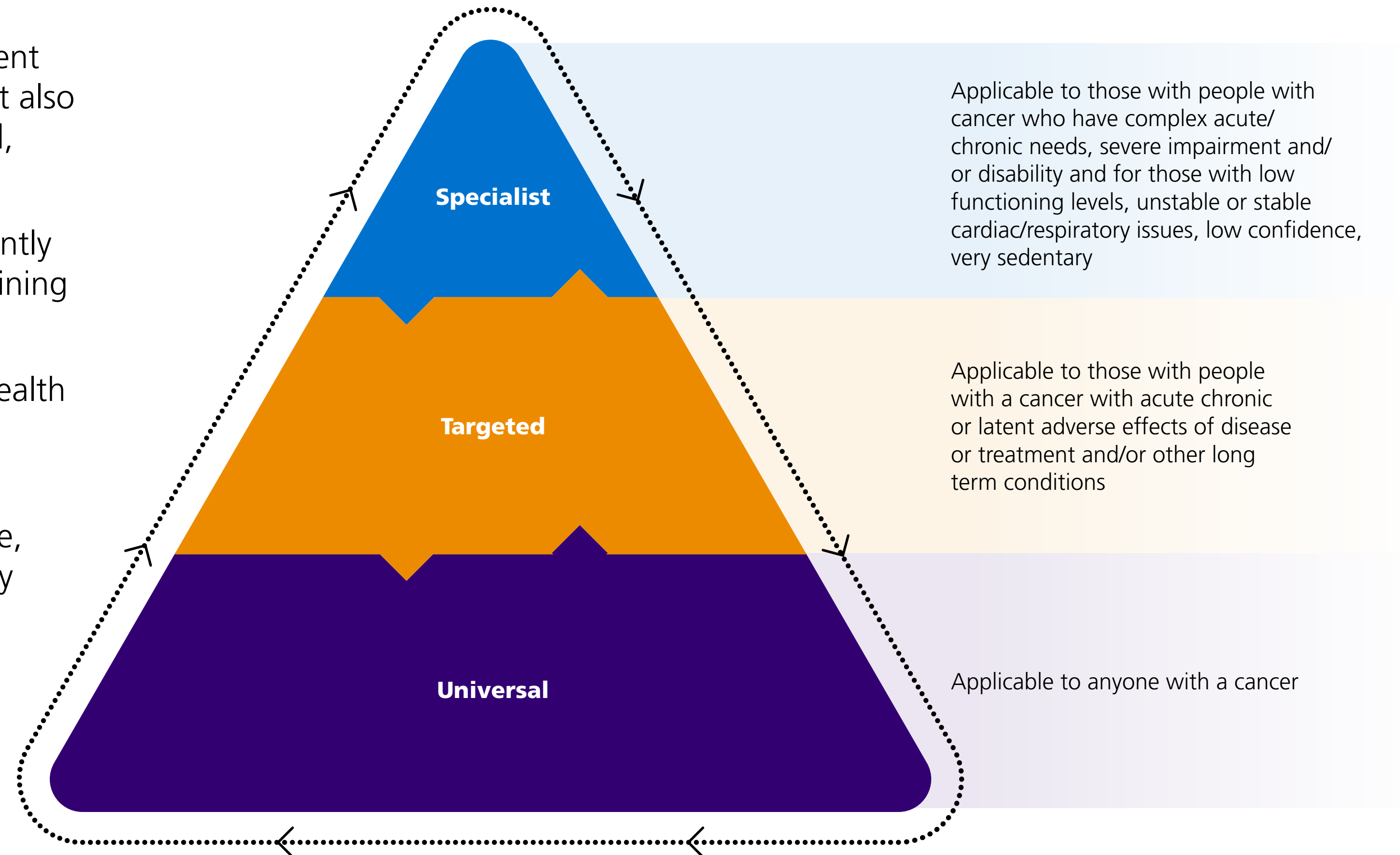
Sometimes a project includes both Prehabilitation and Rehabilitation, supporting patients at different stages of the cancer journey

Delivery of interventions

Universal-targeted-specialist level of care: As the patient need within the intervention increases, the level of support also increases. This provides an increasingly more individualised, and specialist service, towards the top of the triangle.

Specialist interventions: This service is provided predominantly by registered health professionals, often with specialist training in the clinical area.

- Targeted interventions can be delivered by registered health and care professionals or by unregistered professionals under delegated authority.
- Universal interventions can be provided by many people, with the right training and guidance. This is increasingly being provided away from the clinical environment.





Further learning on personalised prehabilitation and rehabilitation in cancer care

- A recent study looked across 2 cancer rehabilitation services in South Wales, highlighting several key factors for supporting staff and patients through a rehabilitation service pathway. This learning could also be applied to other stages of a patients' cancer journey. **Please see the link to this study here:** <https://orca.cardiff.ac.uk/144947/>
- e-Learning for Health (e-LfH) host PROsPeR e-learning explaining Prehabilitation, Rehabilitation, and Personalised care in more detail. **Please access via the link below.** <https://www.e-lfh.org.uk/programmes/prosper/>
- We would like to hear your views about the How to Guide. A team at the University of Southampton are carrying out an independent evaluation of the Guide. To take part in the 10-minute survey, click here: <https://forms.office.com/r/NvVsrgcqrg>

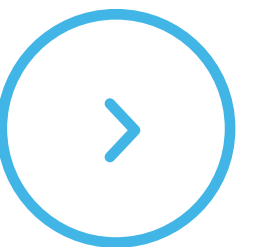


Section 2:

Case Studies

Case studies of Personalised care,
Prehabilitation and Rehabilitation projects

- There are lots of projects across the UK with a focus on prehabilitation and rehabilitation in cancer services.
- Click on a tab below to learn about a project. There is a 'Handy hints!' box next to each project, providing a brief summary of the content.
- Use the search button on the top left of this screen, to put in key words that may be relevant to your area of interest.
- A project from another geographical region, or in another cancer type, may provide the evidence to support your own project.
- Take as much time as you wish, to come back to the case studies as needed.

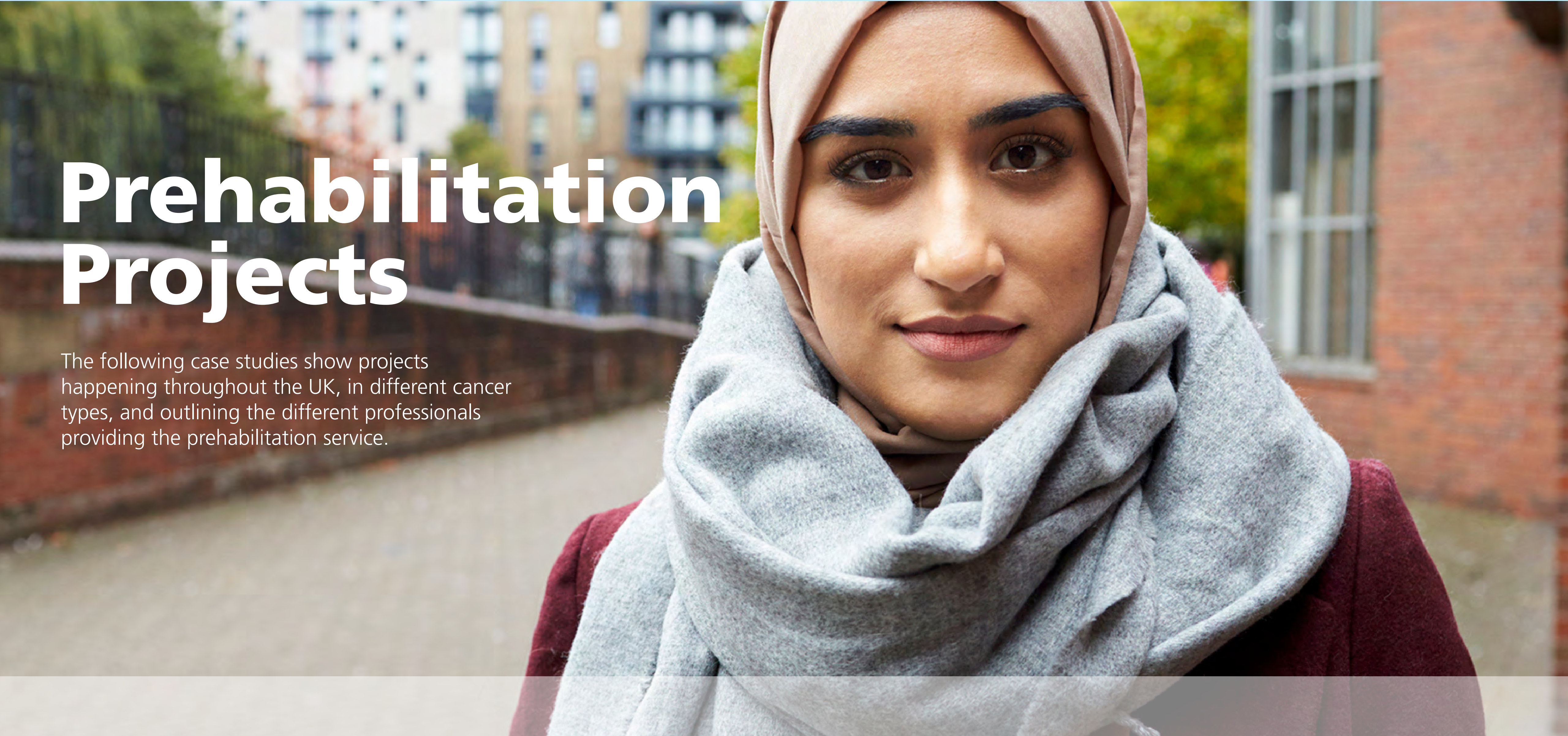






Prehabilitation Projects

The following case studies show projects happening throughout the UK, in different cancer types, and outlining the different professionals providing the prehabilitation service.







Case Study 1

Pre-diagnosis prehabilitation and healthier lifestyle pathway for all cancer types

(Cardiff and Vale University Health Board (CVUHB), South West Cluster)

A new service was developed, running across Cardiff, supporting patients before they receive a positive or negative cancer diagnosis. Those with a positive diagnosis, are referred onwards to other cancer prehabilitation services. However, as approximately 90% of investigations receive a negative cancer diagnosis, this programme provides a great opportunity for public health messages – teaching people about lifestyle changes (for example, smoking cessation, reducing alcohol intake, and healthy eating). This advice can prevent health problems from escalating, or developing in the first place.

Marian Jones, Prehabilitation Pharmacist, was employed to manage the clinical reviews, working closely with Rachel Lee, GP, and primary care lead for prehabilitation work in CVUHB.



Marian Jones
Prehabilitation
pharmacist





Background:

The aim of this project was to optimise the patients journey through the cancer pathway. It was acknowledged that there was a difficulty with traditional funding streams – the funding within primary care (including the first contact for health services, such as GP care), was different to secondary care (acute/hospital). This has previously provided gaps in care, as patients moved across the cancer journey.

Staffing structure for the programme:

The work was established as part of an integrated care hub, keeping costs lower by using existing staffing structures. The exception to this, is the pharmacist role, with Marian employed for this project (as 0.4 WTE), and recruitment for the a further pharmacist to make one full time post.

Development of the pre-diagnosis prehabilitation project:

Patients can initially present to the GP with suspected symptoms of cancer, providing a good opportunity for a health 'MOT', and also arranging onward referral for investigations. The Project Team engaged with GP's - gathering data on the number of patients presenting with cancer-related symptoms, and promoting the service being developed.

Aims for the project: To support patients to establish healthier lifestyle choices, either prior to cancer treatment and therapy (for those diagnosed with malignancy), or in preventing cancer (for those with negative cancer investigations).

Optimisation clinic:

Patients are invited to a further appointment within 48hrs of the initial GP assessment. This reviews comorbidities (e.g. anaemia, hyperglycaemia), to optimise health in preparation for the planned investigations. The investigations are explained, hopefully reducing the number of patients failing to attend their diagnostic scans (15% of patients, at the outset of the project). The impact of lifestyle behaviours are also discussed, for longer term health.

Development of job roles:

Cluster Pharmacist: Marian reported on the potential future role of the new Cluster pharmacist, hoping that this will become a permanent service, using the learning from this project, to embed similar services across different health boards in Wales.

Administration time: Initially the amount of time required for administration of the service was underestimated. Therefore, the team are developing a business case for a Band 4 Support Worker, so the Pharmacists can focus on medication optimisation, and less on administration tasks.

Change in service provision:

COVID-19 had a direct impact on the Optimisation clinic, moving over to a digital platform, meaning staff were unable to perform standard checks such as blood pressure, or spirometry.

Feedback on project: Patients prefer having services close to home, and not in a clinical setting.

Promoting local services can limit expenditure, as this project is mapping what is already available for social prescribing, e.g., fitness classes in a local leisure centre.

Guidance for others:

Provide clarity of the services available: Rachel Lee recommends developing a “bundle of care package” for primary care teams, outlining what services are available, with clear referral routes and pathways. It is important to invest time in this, to ensure optimal engagement from the patient, through ease of access to the different stages of the pathway.

Investment in IT services: to be able to gather data, in an efficient and autonomous way, reporting on this across different health care systems. Also, designing a toolkit, for the different computer systems, to enable service users to access the right care, in the right location, at the right time.

Investment in the workforce – for staff development, planning for the long-term future of the service.

Case Study 2

PRIME Prehabilitation programme

(Royal Surrey NHS Foundation Trust)

PRIME is an AHP led service consisting of Physiotherapy, Occupational Therapy & Dietetics. The programme consists of up to 4 weeks of interventions to prepare patients both physically and psychologically for major oncological surgery.



Case Study 3

HARP Prehabilitation programme in Upper Gastrointestinal cancer

(Ayrshire & Arran)

Jane Holt is the Physiotherapy Team Lead (HARP Project manager & Cardiac Rehabilitation). In this video Jane reports on the Healthy Active Rehabilitation Programme (HARP), and the benefits staff and patients obtain from this programme in Crosshouse, Ayrshire & Arran, Scotland.

Watch Jane's video here



John's Story

John was referred to HARP in December 2019, in preparation for surgery for neuroendocrine gastric cancer. In April 2020, surgery was no longer considered to be a viable option, and his treatment became palliative. John attended three HARP classes prior to the COVID-19 pandemic. After the onset of the pandemic, John received telephone support until he was able to join ROC in the autumn.



**I did do a lot
of walking
*with my wife***



The following is an
interview between
John and Jane:

Q1

Why were you referred to HARP?

I was introduced to Oighrig [Cancer Nurse Specialist] and she explained that we would put a plan together, and that there would be surgery. She mentioned Jane [HARP pilot lead] and that I would need to be physically fit for surgery, which made sense. I wasn't the best at doing exercise, because I worked outside and always felt like I got enough.

Q2

You came along to the classes at first. What did you think of them?

You're in for an hour, but it goes so quickly. It was good that it was busy, with lots of volunteers, and people to help you. I knew the first day I would definitely come back. If there was anything you needed, anything to help you, you'd get it. You got a good sweat up, and everyone kept one another going.

Q3

What other lifestyle changes did you make in preparation for surgery?

I was definitely more active out with the classes. And I stopped smoking, cut down on alcohol. I did do a lot of walking with my wife. With the alcohol and the smoking, I thought the staff are helping me, I'm going to have to help myself. Doing the classes and the walking kept me positive.

Q4

How did lockdown affect you and your treatment?

I was still getting my chemo. There was a good side and a bad side of the lockdown. The fact that the classes were off was a shame, but my wife was furloughed, which was a good result – she was there 24/7, which really helped me. I was also getting the chance to see my son, and my friends and family outdoors.

Q5

Was having telephone contact with a physiotherapist helpful?

Definitely. Every couple of weeks someone would phone and ask how I was. It was good and it made me do it. One time I was at my sister-in-law's and Jane phoned she had me doing a sit-to-stand on the stairs. My wife timed me. Just shows you, even without face-to-face, you can be active with support.

Q6

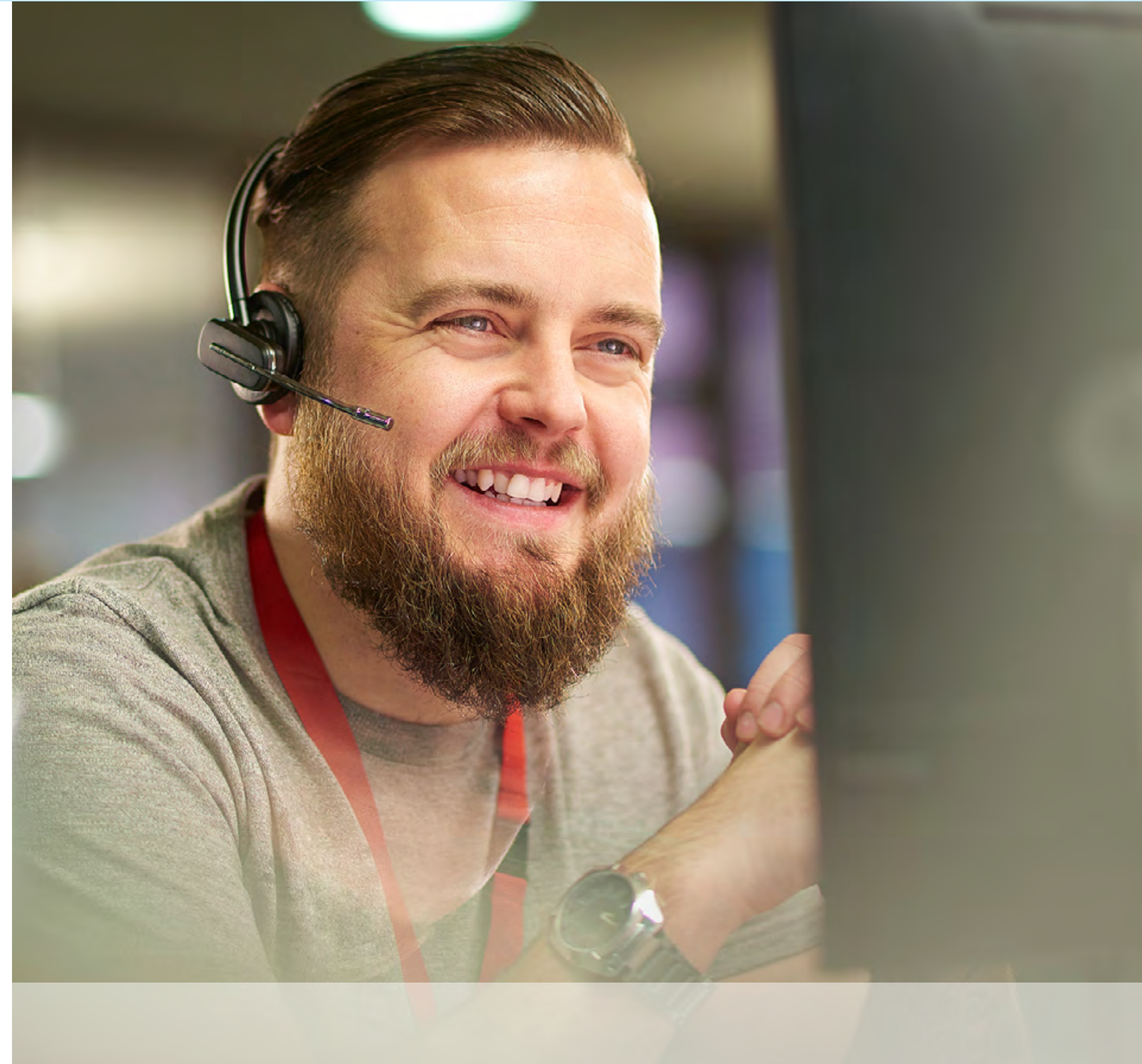
What value did the park visits / walks have?

It really helped, the fact that you could talk, and not just about cancer. It was about the support and the chat. Anything I had an issue with, they dealt with. I met a man there who I knew as a wee boy. I had met him at the classes. It was good to see him again. We chatted, as we have the same cancer.

Q7

What message do you have for others who may be faced with your diagnosis in the future?

Have hope, let it sink in, talk about it. Find out as much as you can. When I was told I was terminal, I felt negative, but just take it day-to-day, and keep thinking you're going to be here the next day. Don't sit brooding, just keep doing things you enjoy. Or go for a walk, because it does clear your head. All you can do is enjoy the quality of life you can just now. You've just got to keep positive.



Case Study 4

Personalised Care Prehabilitation programme (in Colorectal, Gynae, & Upper Gastrointestinal cancers)

(Cheltenham General Hospital)

The programme has just started in Cheltenham General Hospital, under management of the Programme Lead, Juliette Sherrington (AHP Cancer Lead).

Background

A business case was developed using plans from existing Cardiac and pulmonary rehabilitation programmes in the Trust, Holistic Needs Assessment (HNA) data, and focus group feedback – Patients preferred receiving advice from Doctors and Nurses at the diagnostic stage. They were unsure if they would be able to engage longer-term, as “exercise doesn’t fit in with their lifestyle”. A service gap analysis was performed, incorporating personalised care, focussing on what works for the individual.





Where you able to take any personal benefit from your involvement in this project?

Lots, as this was my first major approved project in a new role. I like the feeling of getting it right for our patients, and providing a missing link in their care. It has improved my business planning and project management skills.



Aims of programme

To reduce post-operative length of stay, post-operative complications and 90 day readmission rates (versus baseline pre-intervention data). Improve patient experience and quality of life markers, increasing empowerment for self-management. Longer term, we are looking at outcome measures in the disutility of care.

Content

Referrals provided from the cancer site into the diagnostic team. They inform each patient of the programme, if they are willing to engage, they then receive a telephone call/virtual appointment. This consultation screens for the type of intervention required, and provides consent for enrolment into the programme. COVID-19 was actually initially helpful, as we made good links with services, but these relationships are becoming more difficult as services resume. We are planning to provide a range of services with **universal, targeted, and specialist interventions:**

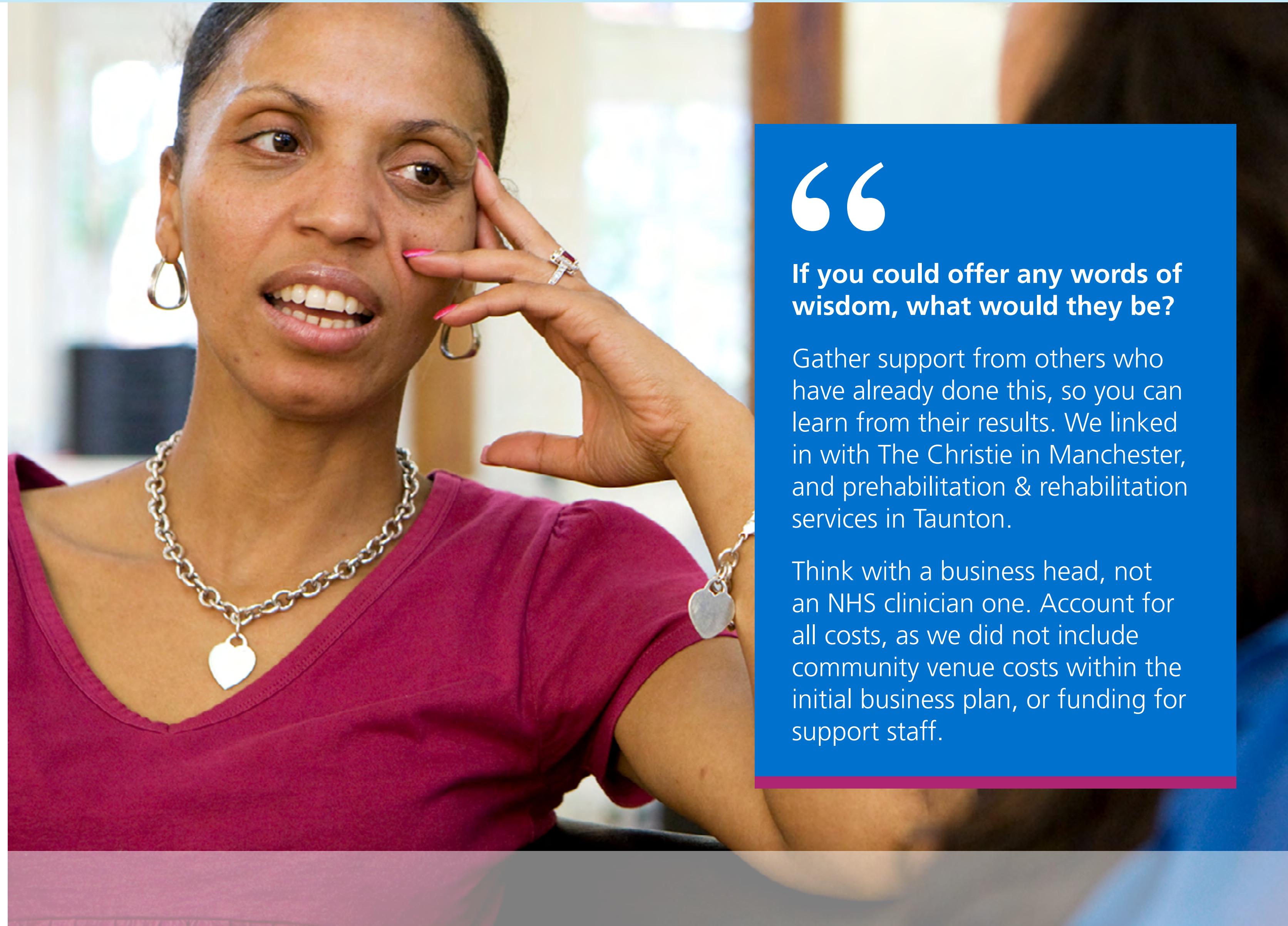
- **We have considered how to engage patients across different communities** (socioeconomic backgrounds, rural communities, and ethnic minorities): Using “Macmillan hub from home” in friendship cafes/resource centres, providing focus groups with ethnic minorities, and engaging with the council to address deprivation.

Engagement to establish the service

We have had good engagement across all stakeholders, all trust partners, CCG cancer teams, Macmillan Cancer Support, etc. There is a need to feedback to relevant teams, and we plan to feedback to the trust board imminently.

Staffing

Recently recruited into Allied Health Professional roles: Physiotherapist, dietitian, and assistant psychologist = funded under Macmillan Cancer Care on fixed term contracts, at 1 WTE (37.5 hours per week). To establish how much admin and support worker time is required, to support referral processes, prior to rolling out to other cancer sites. At the outset the team will design the content of the programme (education sessions), posters to promote the programme, and patient information leaflets.



“

If you could offer any words of wisdom, what would they be?

Gather support from others who have already done this, so you can learn from their results. We linked in with The Christie in Manchester, and prehabilitation & rehabilitation services in Taunton.

Think with a business head, not an NHS clinician one. Account for all costs, as we did not include community venue costs within the initial business plan, or funding for support staff.

Prehabilitation milestones & clinician Reflections



“

Prehabilitation was like a revelation. I really felt like I **was walking a mile in the patients' shoes**.

“

Reading the feedback was humbling, emotional; hearing **the difference we made to quality of life**.

“

I was delighted to see the **outcomes so quickly** and also the wider, positive impact on the health system too.

“

Early screening expedited management - I was really surprised how many were already having problems.

“

Early psychological support - we've **built new relationships** with the counselling team.

“

Leadership development, meeting deadlines, facing and overcoming challenges (difficult conversations, I.T., room, clinician availability/flexibility).

“

Challenging **negative patient beliefs**; managing expectations, difficult conversations (team debriefing after session helpful)

“

Using '**Model for Improvement**' to guide and measure change: I felt challenged, but in a good way.

“

Balancing Measures! It was really valuable to collect information about what we were deprioritising to do the prehabilitation session; helped us demonstrate the unmet staffing/resource need.

“

Creation of the leaflet and radiotherapy video made me feel really proud, it felt so new and ground-breaking. Seeing its positive impact was the icing on the cake.

Case Study 5

Head and Neck Cancer Prehabilitation Project at the North West Cancer Centre

(Derry-Londonderry 2019-2020)

Providing multidisciplinary care to patients with a diagnosis of Head & Neck Cancer. This project won the Innovation category at the Macmillan Professionals Excellence Awards (2021).

How do you receive referrals?

Patients are picked up in the weekly Head & Neck MDM, or they are referred to us after they have consented to radiotherapy.

Content of programme

A 1-2-1 appointment is offered with a Radiographer initially. In this appointment the patient is shown an animated video of the Radiotherapy process, then the patient meets the SLT & Dietitian, before finally meeting the Clinical Nurse Specialist. During these appointments, patients receive targeted therapy, with screening for swallowing issues (SLT input) or nutritional markers (Dietitian input).



Hear more about this project from **David Curtin, SLT**, in a video recording [here](#)



By providing interventions earlier in the patients journey:

- Appropriate patients were referred for **specialist intervention** prior to radiotherapy treatment (for swallowing issues, malnourishment or anxiety). This reduced the need for anxiety medication (versus pre-pilot).
- Higher attendance at outpatient appointments, as the patients reported to understand the role of each health professional better from the start of the journey.
- Increased empowerment to manage symptoms independently (requesting earlier discharge from hospital and efficacy in following treatment/guidance)
- Admission rates to hospital were 30%* lower than in persons not receiving interventions
- For those admitted to hospital, length of stay reduced by 20%* (with patients keen to manage independently at home (*data gathered from 10 patients in the pilot)





In the pilot, patient feedback was gathered on the project:

“ I understood what everyone’s role with me would be and the leaflet broke down the side effects week by week, so there were no surprises or shocks.

“ My swallowing problem was assessed fast, and the SLT/Dietetic advice helped me to eat better and stop worrying.

“ I’ve stopped smoking after 40 years, never thought I could do it - thank you!

“ I think if I hadn’t spoken to the counsellor after the CNS referred me, I would have pulled out of the treatment altogether.

“ My wife and I stuck the leaflet on the fridge and looked at it when I was experiencing a new side effect, seeing it was a normal reaction to radiotherapy stopped us from panicking and calling the out-of-hours helpline.

“ I started my mouth and swallowing exercises straight away. I then had some more questions about these before the treatment began and having someone to contact was really reassuring.

“ The radiotherapy video showed me what was going to happen and so it took the fear away, it also helped me to explain it to my wife afterwards.



Staffing for the Head and Neck Cancer programme

Radiographer, Speech & Language Therapist (SLT), Dietitian, and Head & Neck Clinical Nurse Specialist (CNS) managed the project delivery. Patients were also referred to the counselling service, physiotherapy, and occupational therapy as appropriate.



David Curtin
(SLT)



Angela McKeever
(Head & Neck CNS)



Malcolm Wilkinson
(Radiographer)



Ciara McSherry
(Dietitian)

Case Study 6

Specialist Prehabilitation before major Colorectal and Upper GI cancer surgery

(Wrexham Maelor Hospital [BCUHB])

Neil Agnew (Consultant Anesthetist, BCUHB) developed and managed the prehabilitation programme, in Colorectal and Upper Gastrointestinal (UGI) surgical cancer patients. He has outlined the work provided in this programme as below:

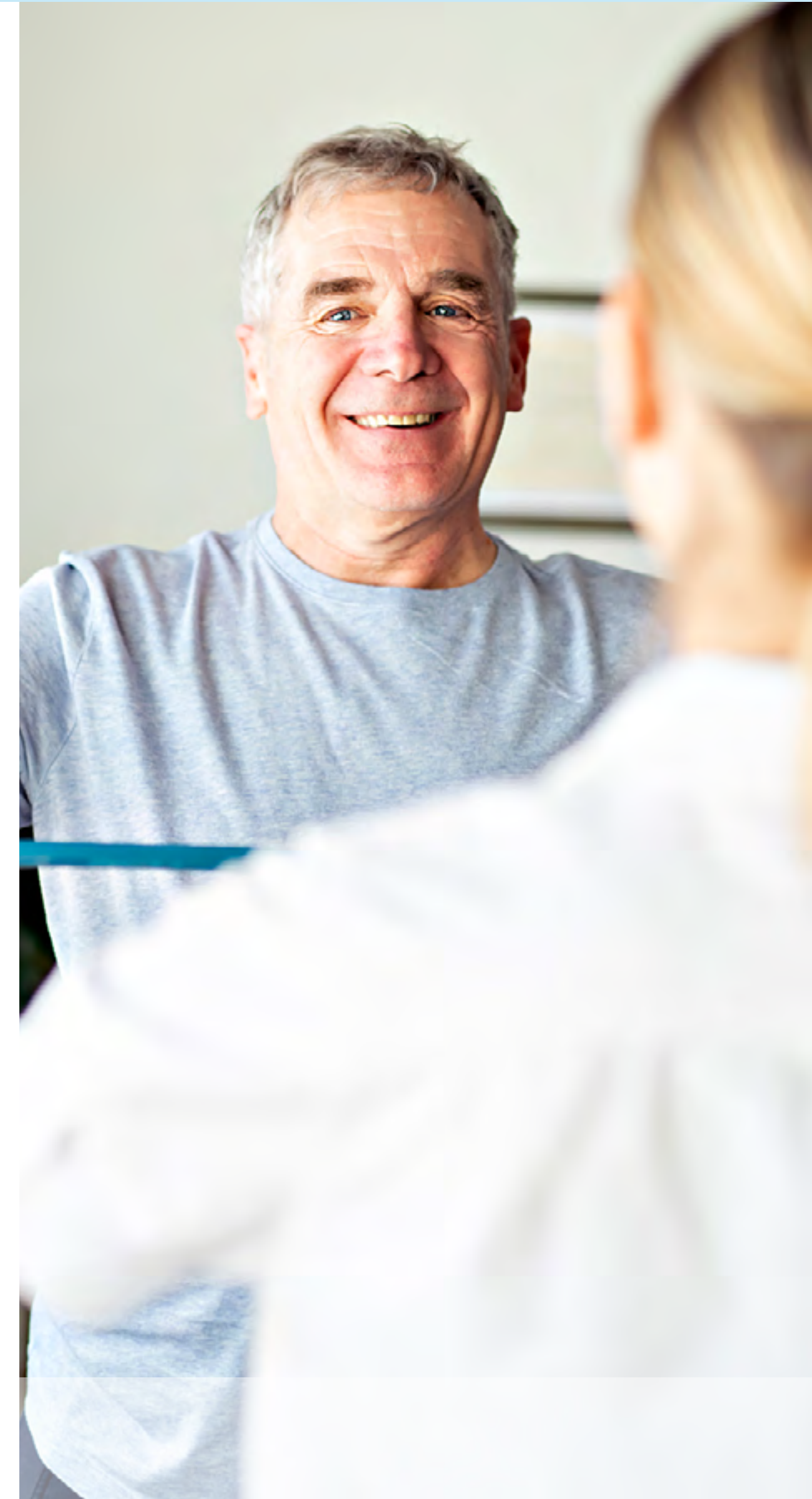
Introduction to programme:

Patients referred by the Surgical Nurse Specialist, following the cancer diagnosis or multidisciplinary assessment, are walked around to the early preoperative assessment clinic, for a full health assessment. Within this assessment, patients are invited to enrol onto a 4 week prehabilitation programme. A cardiopulmonary exercise test is arranged, and patients are provided with a food diary to complete. They are booked into the next prehabilitation initial assessment, to plan their bespoke regime.

Specialist Prehabilitation programme:

At each session, running at Wrexham Maelor Hospital over 3 half days per week, patients receive:

- High intensity interval exercise, core strength, balance exercises and inspiratory muscle training, supervised by Physiotherapists, within a home-based exercise programme (for the days in between attendance at the hospital).
- Dietitian assessment and optimisation of nutritional intake to address malnutrition, and augment response to their exercise programme.
- Psychological assessment, supporting and motivating patients to cope with their cancer diagnosis, and improve their lifestyle in preparation for surgery.





Data collection:

- A maximum of 4 new patients per week are enrolled, giving a group size of 16, on the 4 week rolling programme.
- 75% invited, have engaged with the service, enrolling into the prehabilitation pilot (n=49)
- **Demographics:** Age, sex, weight, American Society of Anesthesiologists (ASA) classification, smoking status, type of surgery offered
- **Anaemia:** Haemoglobin (Hb), Transferrin saturation
- **Exercise:** Exercise tolerance: CPET (maximum heart rate), Peak VO2 (maximum oxygen uptake), Maximum inspiratory pressure on power-breathe IMT (inspiratory muscle training), 6 minute walk test, Timed up and go test.
- **Psychological:** Hospital anxiety and depression score, 10 point visual analogue health score
 - » Free text patient feedback
- **Nutritional:** Grip strength, Daily protein intake and food diaries, SGA (Subjective Global Assessment) nutritional screening
- **Surgical data:** Hospital Length of stay, Critical care length of stay, Complications, Mortality
- **Outcomes** (49 prehabilitation patients, compared to 47 patients not enrolled onto programme)
 - » 2.5 day average reduction in length of stay, and 1 day less on critical care; complication rates post-surgery halved. Great patient feedback, 85% returned for a post-operative session (for signposting to ongoing healthy lifestyle advice), and there was a 90% adherence to programme.

Funding:

6 months pilot, with business planning to expand to permanent Specialist Prehabilitation services. The initial funding was provided by Wrexham Maelor Hospital, BCUHB, with contributions for equipment from the Shooting Star Cancer Support charity. The plan is to roll out the funding to establish 3 specialist prehabilitation units across North Wales, as well as establish community based universal prehabilitation at the point of GP referral.

Staffing:

The funding supported the full time staff structure:

- Band 7 Clinical services therapies lead
- Band 6 Occupational Therapist
- Band 6 Dietitian
- Band 5 Physiotherapist/Exercise physiologist
- Band 4 Physiotherapy Technician
- Band 3 Administration support

This was in combination with support from Consultant Anaesthetist, Link nurse from preoperative assessment and project management services.



“

If you could provide some key tips for others starting a similar prehabilitation project, what would they be?

Get senior management on board early, to help with the progress of the business case. Support from IT is required to help establish virtual remote sessions, and a website to provide information to patients. Do not underestimate the importance of staffing, particularly administration support, which is essential.

Have plenty of patience, as it can take 2-3 years to set up the service.

Case Study 7**Prehabilitation programme in primary Lung, Colorectal, & Head and Neck cancers**

(South Eastern Health and Social Care Trust, Northern Ireland)

The 'Cancer Prehabilitation Programme' is an exercise, nutrition, emotional and wellbeing programme, designed by a team of professionals and exercise experts, based on latest research. Dr Cherith Semple (Reader in Clinical Cancer Nursing, Ulster University/Ulster Hospital), takes us through the programme in more detail.

This innovative health & wellbeing programme for cancer patients, runs in the South Eastern Trust area of Belfast, as a partnership between the Trust, local councils, and Ulster university.

Please click on the following links to learn more about the programme:





Referral criteria for the Cancer Prehabilitation programme:

- Cancer diagnosis (primary lung, colorectal or head and neck)
- 18 years old and above
- Registered with a GP
- Ability to access the programme either independently, or with support from a carer/ family member
- Has indicated informed consent to be referred
- Readiness to engage in a personalised physical activity programme with support
- Patients' consultant confirm suitability for cancer Prehabilitation
- Offered curative treatment for colorectal and mouth cancer, and suitable for surgery

Or, Diagnosis of lung cancer: a) offered curative intent treatment options, including surgical resection and curative intent oncology treatments (SABR, radical radiotherapy chemo radiotherapy)

Or, b) Lung Cancer Palliative patients on palliative treatment, including:

- ECOG performance status 0-2. The ECOG score describes a patient's level of functioning in terms of their ability to care for themselves, daily activity, and physical ability (walking, working, etc.).
- Clinical frailty score ≤ 5

The intervention will be adapted (with **targeted** therapy) for those patients in whom the cancer has spread to the bone, with reduced immunity levels or an abnormal blood count (biochemical data).

Role of the Multidisciplinary team (MDT):

- **CNS** – assessment, screening, referral – patient education on what Cancer Prehabilitation is
- **Multimodal care** – delivering **universal and some targeted components** – exercise, nutrition and emotional wellbeing
- **Physiotherapist** – pelvic floor exercises for a subset of colorectal patients and specialist exercise
- **Macmillan Health and Wellbeing team** – targeted emotional support
- **Assistant Psychologist** – **Specialist** Emotional Support
- **Head and neck CNS, dietitian and SLT** (initially) deliver a one-stop clinic for head and neck cancer patients having major surgery
- **Dietitian** - **Specialist** nutrition pathway
- **Smoking cessation team** – referral for patients who are current smokers
- **Substance Misuse and Liaison Team** – alcohol assessment and advice for those screened 5+ on Audit C tool



Case Study 8

Lung Cancer Prehabilitation services

(Barts Health NHS Trust, England)

Dr Will Ricketts, Consultant Chest Physician, Barts Health NHS Trust, takes us through the details of this project:

Intervention

Prehabilitation service for early stage lung cancer, in patients with borderline fitness. The prehabilitation programme enables surgery to take place, improving fitness prior to curative surgical resection.

Background

Poor cardiorespiratory fitness from Chronic Obstructive Pulmonary Disease (COPD) and is the primary cause of poor recovery after surgical resection, and for others being classified as inoperable.

Aim

Primary aim was to improve resection rates to reduce mortality (by improving fitness for surgery, reducing post-operative complications and hospital length of stay).

Programme

COPD is common in lung cancer patients (with cigarette smoking as a shared risk factor). Existing COPD programmes were used in project development, incorporating progressive muscle resistance training and aerobic training, including: Optimising inhaled therapy; Smoking cessation; Pulmonary rehabilitation. Dependent on patient choice, patient need and availability, programmes are provided one-to-one or as group sessions. Post-operatively all patients were offered onward referral to local pulmonary rehabilitation services on discharge. The median duration of the programme was 22 days, but the earlier patients are referred, the longer the course of prehabilitation they can receive.





This prehabilitation programme is the first to address the fitness of patients, who may otherwise not be able to receive lifesaving surgery.

Outcomes

This prehabilitation programme is the first to address the fitness of patients, who may otherwise not be able to receive lifesaving surgery. The median duration of the programme was 22 days, but “the earlier patients are referred, the longer the course of prehabilitation they can receive”.

As reported in the National Lung Cancer Audit, rates of surgical resection have improved from a negative outlier (12.8%) at implementation of the programme, to achieving the highest resection rate in the country (33.3%)¹. No increase in mortality or length of stay in the acute setting was observed. There was no significant delay in the 62-day treatment pathway.

Physical and quality measures also showed statistical improvement in:

- 6-minute walk test distance
- 5 times sit-to-stand time
- Forced expiratory volume in 1 second (FEV1)
- EQ-5D-5L

Funding

Dr Will Ricketts recommends:

- Making links with your local services to negotiate fast-tracked referrals. This can keep costs low, using existing programmes (e.g. smoking cessation and pulmonary rehabilitation), and existing staffing structures. This programme was led by the Oncology Outpatient Physiotherapy team, and across the pathway also included intensive inpatient prehabilitation (a Cardio-respiratory Physiotherapy service) and standard Pulmonary Rehabilitation (under the Community Respiratory Team).
- Investment in administration staffing required to manage referrals.
- Investment in digital app for patients, e.g. Living With

Rehabilitation Projects

The following case studies show projects happening throughout the UK, in different cancer types, and outlining the different professionals providing the rehabilitation service.





Case Study 1

Beacon Plungers Swimming rehabilitation following breast radiotherapy

(Musgrove Park Hospital, Somerset NHS Foundation Trust)

The Beacon Plungers aim to improve functional capacity in those recuperating from breast cancer, providing lifelong skills to self-manage pain, lymphoedema, and improve the range of shoulder/arm movement following radiotherapy. **Lisa Durrant (Macmillan Consultant Therapeutic Radiographer for radiation late effects) & Carrie Beasley (Physiotherapy Assistant and Navigator for Cancer Prehabilitation and Rehabilitation)** talk us through the main points in the programme:

The background to the 'Beacon Plungers':

Swimming is beneficial to breast cancer and lymphoedema patients, reducing neck, shoulder and axillary pain (Cantarero-Villanueva, et al., 2013). Potential participant feedback was gathered during development stage of the programme. They stated they were unlikely to use their local swimming pool, due to body image concerns, and perceived infection risks. Support on the correct exercise plans was also required.

The programme addressed these issues, with rehabilitation exercises taught initially in the privacy of the hospital hydrotherapy pool, for 3 x 40 minute sessions once per week. Following this, they are invited to attend 6 private sessions at a local public pool, to consolidate their knowledge and interact with peers. Hormone therapy and sexual health workshops have been held when the pool was shut for repairs.





Carrie Beasley (Physiotherapy Assistant and Navigator for Cancer Prehabilitation and Rehabilitation)

Who did you engage with for the development of the service?

The patients; Healthcare staff in primary care (lymphoedema service) and secondary care (radiotherapy, physiotherapy); Third sector partners (Macmillan Cancer Care and a local school swimming pool); Local CCG engagement ensured outcomes were fed directly to the cancer and social prescribing commissioning teams.

What are the funding routes associated with the programme?

Macmillan paid for the physiotherapist and the late effects team to attend the private weekly session at a local school swimming pool. Participants self-fund the swimming sessions in this local pool after this.

Data collection

Over 80 participants have enrolled onto the programme (in November 2021). To benchmark the service, clinical data, demographics, functional measurements and validated questionnaires were used. The following data continues to be collected in each participant:

- Range of shoulder and arm movement
- QuickDASH for arm, hand and shoulder function
- QLQ-30 for cancer specific quality of life
- EQ-5D-5L for general quality of life
- LymQol arm for lymphoedema burden
- PAM (patient activation measure)

Outcomes: For 33 participants:

- Age 37-86 years, 4 – 165 months since diagnosis
- 79% experienced shoulder problems, 55% lymphoedema, and 76% frequent pain - All showed an improvement in range of movement of the shoulder following hydrotherapy. This was sustained or improved at the public pool (14 patients).
- Quality of life metrics improved, with reduced referrals to outpatient services for pain and fatigue, lymphoedema and counselling.
- **Counselling Service feedback:**
"We usually offer 6 sessions for counselling, but some of the [women attending the Beacon Plungers Group] are only needing 2-3 sessions of counselling. I suspect this is due to the connection with others, releasing the natural endorphins and... seeking support from each other. The Beacon Plungers sessions have really helped to move the clients... through a physically and emotionally challenging time, in a safe and gentle manner. It's great when we can work together like this."

Feedback from the Late Effects Team

Lisa Durrant reports on the experience for the team: *"Being able to listen and engage with participants, understanding their daily challenges, aspirations and concerns, has profoundly changed the way the team think about personalised care, and what we can offer to participants entering the scheme."*

Are there any key learning points that you would like to share with others?

Consider using a non-NHS outpatient setting – this was vital to address medical queries in a relaxed environment, and to provide a recognised person to introduce new members to the Plungers team.





See some of the **'Beacon Plungers'** talking about the programme



Feedback from participants

"The physio works, with proof from measurements taken before Covid and on return to the pool. And the people, we laugh together, we cry together, we understand together... And sometimes we eat cake together."

Vikky

"These people understand what it's like, not only to have breast cancer, but to live in fear every day of it coming back, in a way that none of my other friends or family understand. We can swim in an environment away from the usual pool setting, where we don't have to worry if our knitted knockers float up to the surface of the water... Without the Beacon Plungers I don't think I'd swim. My arm would suffer, my mental health would suffer, and I wouldn't have this amazing group of women. I will be eternally grateful that I met Lisa and that she invited me to join the Beacon Plungers."

Claire

"A diagnosis of breast cancer and subsequent treatment left me feeling very isolated, with high anxiety and fear. I felt vulnerable, tired and fatigued. I had lost confidence, and had a lack of trust in my body. The first session tested my confidence greatly, but... I was welcomed by a group of lovely ladies who I immediately identified with. When we need it, Lisa and her clinical team are there to support us, and answer our questions. The sessions have encouraged me... to develop my self-confidence again."

Hazel

"it's FUN, providing support from those who have experience of breast cancer. No one understands better than someone who has been through the same experience."

Carol

Case Study 2**Rehabilitation as part of a patients palliative care cancer journey**

(St Joseph's Hospice, Hackney, London)

Sirlene is a 67 year old female patient, receiving outpatient and inpatient care under St Josephs Hospice. Catherine Hegarty (Palliative Care Physiotherapist, at St Josephs Hospice) is supporting this care. This is a summary of Sirlene's care:

Current relevant medical issues:

Myeloma (Kappa Light chain) – soft tissues deposits, ongoing chemotherapy (palliative care, rather than curative); COVID-19 (January 2021); Fractured femur due to myeloma deposits (surgically treated November 2020, and June 2021).

Social:

Lives alone with a supportive friendship and family network.





Sirlene received rehabilitation support from St Josephs' Hospice in different ways, as outlined below:

- Initially admitted to hospice via COVID-19 pathway - set up to admit patients from local hospital, requiring ongoing rehabilitation (such as Oxygen support/weaning). Sirlene required functional rehabilitation to wean from oxygen (including exercises and clearly outlined goal setting).
- Discharged home – Empowered Living Team provided community rehabilitation at home, supported by goal setting, and through volunteer input.
- Admitted to acute hospital with fractured neck of femur, requiring surgical intervention and rehabilitation. Informed that myeloma was progressing with metastases. A 2-week respite and rehabilitation stay was arranged in St Josephs Hospice (following discharge from the hospital).
- Discharged from hospital, and Sirlene expected to receive community Occupational Therapy and Physiotherapy support at home. This care was not provided.
- Catherine (St Josephs Hospice Physiotherapist) restarted physiotherapy support at home – rehabilitation to regain range of movement, strength and improve mobility.
- Admitted for respite/rehabilitation – Physiotherapist referred for inpatient care, for higher intensity rehabilitation than was possible to provide in the community. Had 2 weeks hospice stay, with personalised goal setting.
- Discharged home with shared care between community and inpatient Hospice teams - Planning further inpatient stays for rehabilitation / respite over the coming months
- Referred for day hospice care (to access other hospice services, and to receive additional physiotherapy to the services provided at home, and gym group sessions)

Hear from
Sirlene here



Case Study 3

Feedback from a bowel cancer patient and his spouse on the Prehab4Cancer programme

(Greater Manchester)

Ian was diagnosed with bowel cancer, receiving surgery in hospital. He was referred to a rehabilitation programme to increase exercise tolerance after the surgery.



Case Study 4

MDT Long Term Follow Up Clinic for Children and Young People, following treatment for brain tumours

(Great Ormond Street Hospital [GOSH])

The clinic is provided for children and young people (CYP) when they are 5 years post treatment for brain tumours. This **targeted/specialist** clinic supports CYP and their next of kin through the long term effects of treatment. Eligible patients are invited to attend the clinic, running on the 1st and 5th Tuesday of every month, with an allocated appointment time.

Vicky King (Occupational Therapist), and Danny Bell (Physiotherapist) in Neuro-oncology team, talk us through the programme provided at GOSH:



Staffing:

The GOSH multidisciplinary team (MDT), providing cover to this clinic, includes the following staff:

- Up to 3 neuro-oncologists
- 2 CNS (until Dec 2021)
- 1 neuropsychologist
- 1 psychologist
- 1 endocrinologist
- 1 physiotherapist
- 1 occupational therapist



Background to the intervention

The number of children and young people (CYP) surviving brain tumours is increasing annually, with 5 year survival having nearly doubled over the past 40 years. However, more than two-thirds of these survivors have multiple long-term co-morbidities (“late effects”) resulting from their tumour and/or treatment(s), necessitating lifelong follow-up from multiple professionals. We know transition into adulthood for this cohort has been lacking.

Please outline the intervention

The first clinic began in January 2020 as a collaborative effort between healthcare professionals in the neuro-oncology, endocrinology, psychology, neuropsychology, physiotherapy and occupational therapy departments. Clinics ran once to twice-monthly throughout the year, and apart from a 6-month period during the COVID-19 pandemic, all appointments were carried out face to face. CYP and their families are encouraged to ask questions, and to take control of their own health in preparation for adulthood.

1



Each patient is screened prior to clinic to work out which professionals need to attend

2



CYP and their families are provided with information prior to the clinic, and an optional questionnaire (asking how the clinic could support them).

3



During the clinic, CYP are able to ask questions, and explore any issues related to their previous treatment, their health, growth, puberty, motor skills, emotional well-being, learning, vocation, or independent living skills.

4



After the clinic, the MDT escalate issues raised, including liaison with education, local paediatric therapy, and adult services (if available).

What were the intended outcomes for the project?

"We sought to establish a collaborative MDT 'one-stop' long-term follow-up clinic for CYP who were >5 years from the end of treatment of a brain tumour to reduce the need for multiple hospital appointments and to provide holistic assessment and supportive care, including transition into adulthood."

Background to the intervention

Over 18 months, a total of 61 patients have been seen in 111 appointments. In these appointments, patients accessed a range of services, including:

- Neuro-oncology
- Endocrinology
- Neuropsychology
- Physiotherapy/ Occupational Therapy
- Psychological services

Other specialties accessed, in addition to the clinic, include:

- Ophthalmology
- Audiology
- Neurology
- CAMHS



“

Feedback from CYP and their families has thus far has been overwhelmingly positive, with all leaving feeling 'very satisfied' or 'satisfied'."

Feedback from the team: "The MDT have expressed personal satisfaction with the holistic outcomes, made possible by having all team members present. Watching the CYP prepare for their adulthood following a brain tumour is inspiring, and hearing about the range of late effects has been eye-opening. It helps us to reflect on how we support families, going through brain tumour treatment right now. The team plan to continue developing the clinic, including improving links with adult services, and to trial different models of staffing, and reviewing the location of where services are provided."

Case Study 5

Post Treatment & Late Effects Service for Head and Neck cancer

*(Nottingham University Hospitals
NHS Foundation Trust)*

Emma Hallam (Macmillan Consultant
Therapeutic Radiographer) outlines
the Post Treatment and Late Effects
programme provided to Head and
Neck cancer patients.



Prehabilitation and Rehabilitation Projects

The following case studies show projects happening throughout the UK, in different cancer types, and outlining the different professionals providing a joint service across prehabilitation and rehabilitation.







Case Study 1

CARE (Cancer and Rehabilitation Exercise) at Notts County Football Club

Josh Stevenson - Programme Coordinator, Alex Flak - Programme Officer

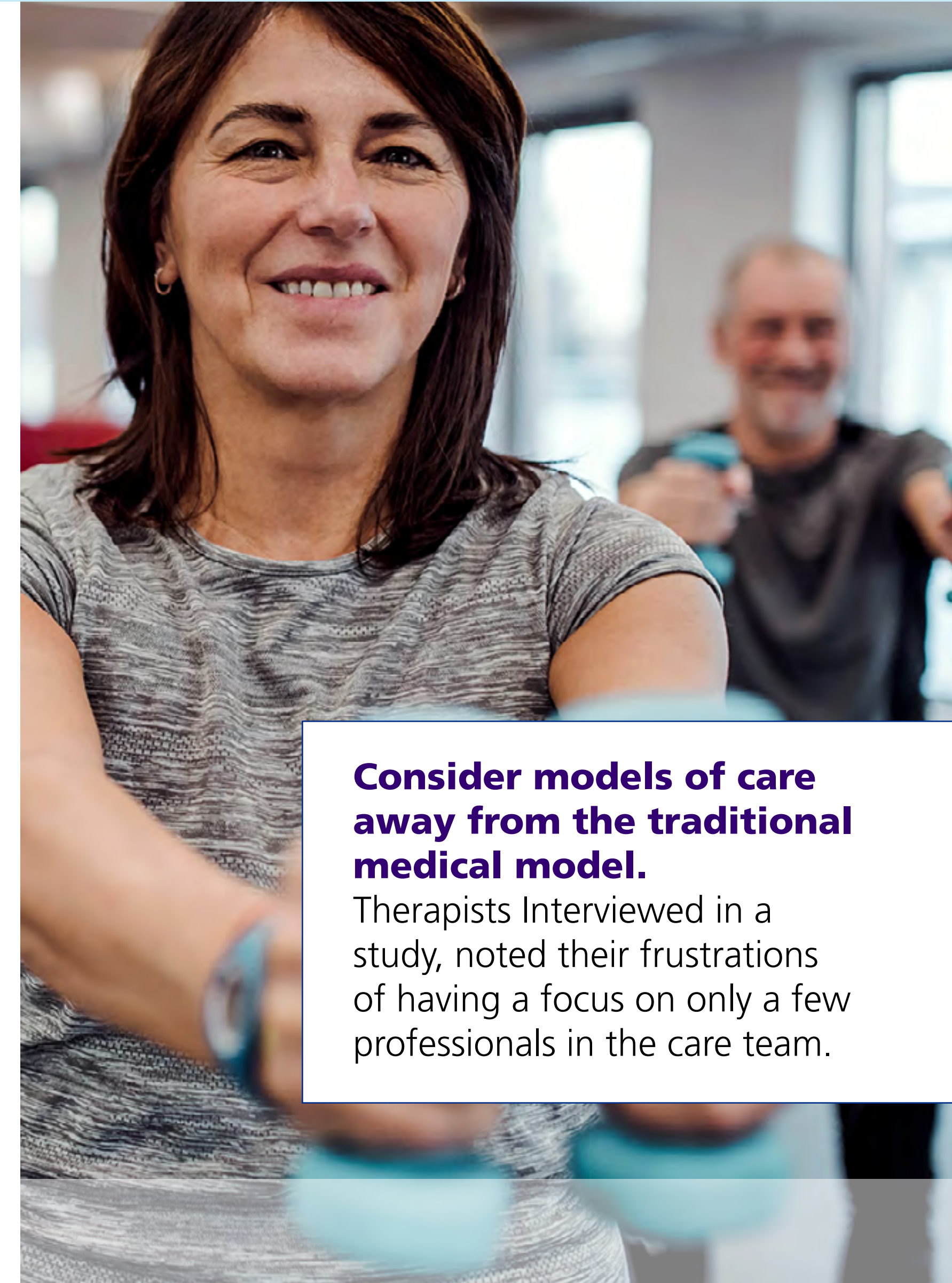
The Cancer and Rehabilitation Exercise (CARE) Programme has been running for over 7 years, funded by Macmillan Cancer Care, CityCare, and the East Midlands Cancer Alliance. The programme is designed to support cancer patients through any stage of their cancer journey (preparing for treatment, through to living with or beyond cancer). Group-based exercise offers social and psychological support, provided by qualified physical therapy instructors in cancer rehabilitation. **Josh Stevenson, Programme Coordinator, talks us through the programme:**

Please outline the main benefits of this programme?

Participants are able to join a community of individuals going through similar treatments, for group-based exercise to improve physical performance, tailored to the specific needs of the individual.

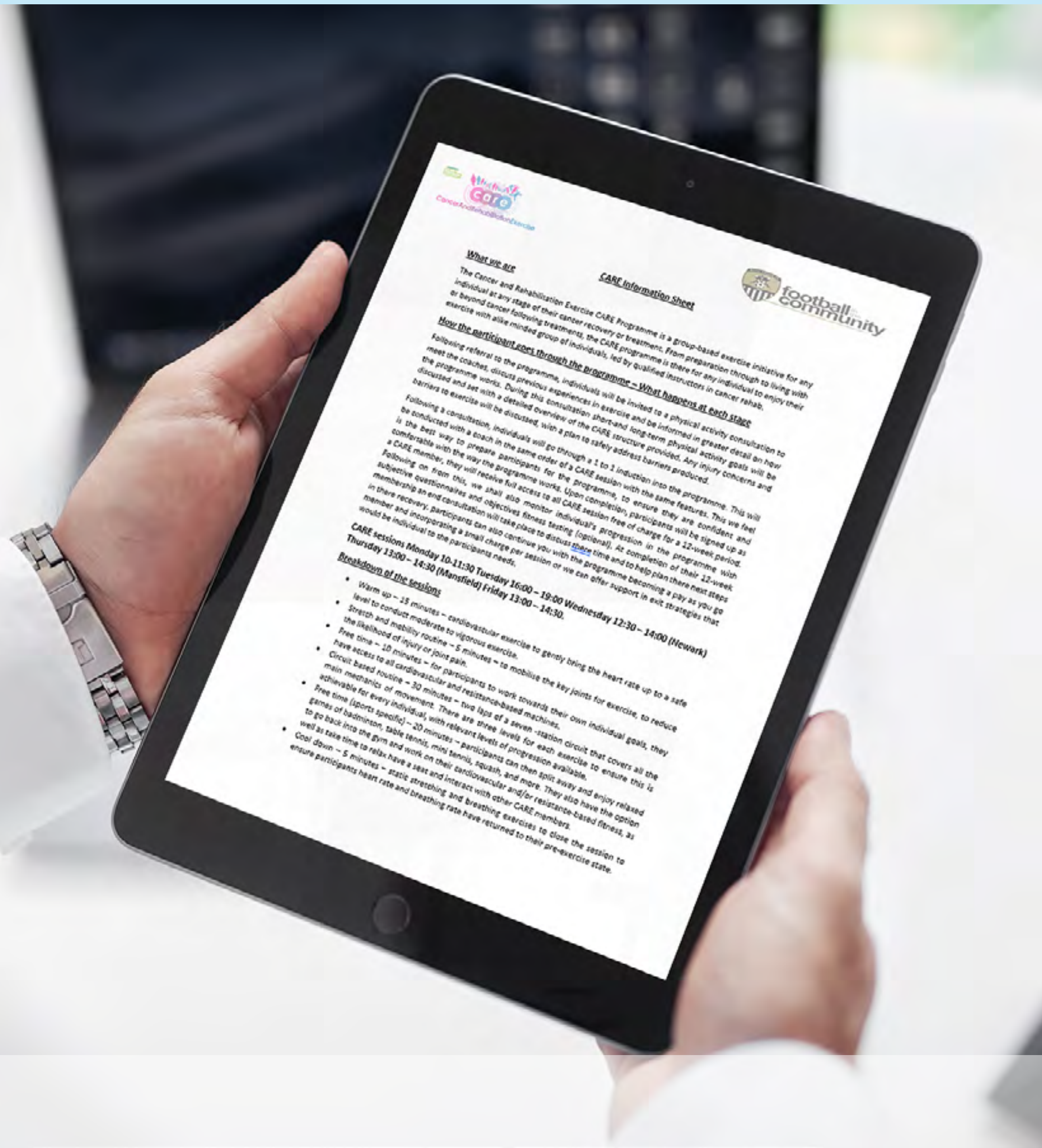
What is the aim of CARE?

The programme aims to reduce fatigue, and promote muscular strength, to perform a wide range of everyday activities. This is especially important as we age, or as we recover from a variety of cancer treatments.



Consider models of care away from the traditional medical model.

Therapists interviewed in a study, noted their frustrations of having a focus on only a few professionals in the care team.



How do you receive referrals?

They are self-referred, or from a specialist, such as Cancer Nurse Specialist, or Consultant Oncologist.

How do participants engage with the programme?

They are invited to a physical activity consultation, to meet the physical therapy coaches when an information leaflet is provided

- Previous experience of exercise is discussed, with a detailed overview of the CARE programme
- Injury concerns or barriers to exercise are clarified
- Short-and long-term physical activity goals are agreed
- Individuals receive a 1 to 1 induction of the activity provided in the programme, in the same order as a CARE session
- Participants are signed up as a CARE member, receiving CARE sessions free of charge for a 12-week period
- Progress is monitored with optional subjective questionnaires and outcomes (fitness testing)
- A final consultation happens at the end of the 12-week membership. To continue with the programme, participants can either pay a small fee per session, or we support them to manage their own exercise plan.

What is the agenda of the programme?

Daily lifestyle activities are provided, completing a range of chair-based exercises with a Thera-band at home. Additionally, CARE sessions run Monday – Friday, at specific times through the daytime and into the evening in the gym:



**Learn more about
the programme here**

Exercise sessions with the physical therapist



Warm up – 15 minutes:

Cardiovascular exercise to gently bring the heart rate up to a safe level to conduct moderate to vigorous exercise.



Stretch and mobility routine – 5 minutes:

To mobilise the key joints for exercise, to reduce the likelihood of injury or joint pain.



Free time for exercise – 10 minutes:

To work towards individual goals, with access to all cardiovascular and resistance-based machines.



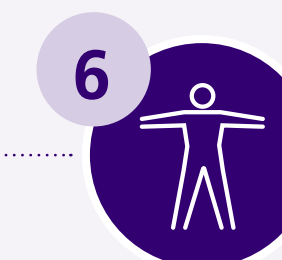
Circuit based routine – 30 minutes:

Two laps of a seven-station circuit, covering all the main mechanics of movement. There are three levels for each exercise, matched to each individual, as they progress.



Free time – 20 minutes:

Relaxed game of badminton, table tennis, mini tennis, squash, etc, or a gym session to work on cardiovascular and/or resistance-based fitness. Or, time to relax and interact with other CARE members.



Cool down – 5 minutes:

Static stretching and breathing exercises to close the session to ensure participants heart rate and breathing rate have returned to their pre-exercise state.



What literature do you provide?

A Mobility and Flexibility Exercise booklet is provided, for those starting with low intensity exercise, providing chair based exercises with images. We also advertise the programme with a 'CARE postcard'.



How many participants have you supported?

Over 500 cancer patients, with reports of feeling fitter, improvement in stamina related to activity, combatting and dealing with cancer fatigue. Other outcomes include ability to return to work, and decreased levels of anxiety and depression.

What guidance do you have for others?

Make strong links to **specialist care** teams to ensure patients are referred onto the programme. Utilise the resources already available – making good use of the community setting, supporting instructors to be trained in cancer rehabilitation. Make a clear declaration in the paperwork provided to patients, that they are liable for their own health, and should seek guidance from a health professional if needed.

Case Study 2

Prehabilitation & Rehabilitation programme Live Active *Renfrewshire*

Live Active works with any person in the Greater Glasgow and Clyde area, who is currently inactive at the time of referral.

People receive bespoke advice and encouragement to work towards lifestyle changes, such as increasing physical activity levels, or making positive changes to their daily routine. Live Active Advisors work with people over a 12 month period, with support from one to-one consultations (in person or over the telephone), and providing an exercise programme in the leisure centre. A summary of the programme / referral pathways is available here: **Live Active flowchart**.



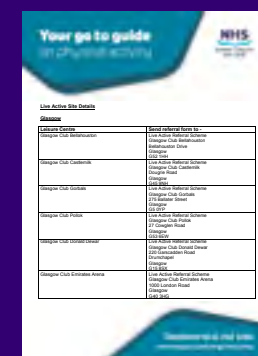
This video explains how the programme adapted during the COVID-19 pandemic



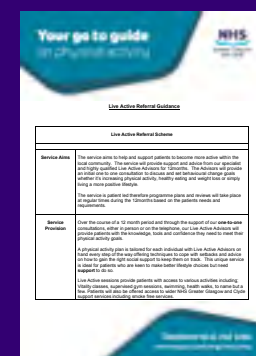
Links to paperwork for LiveActive:



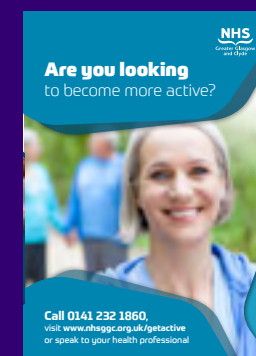
Live Active
Referral Forms



Live Active
Site Details

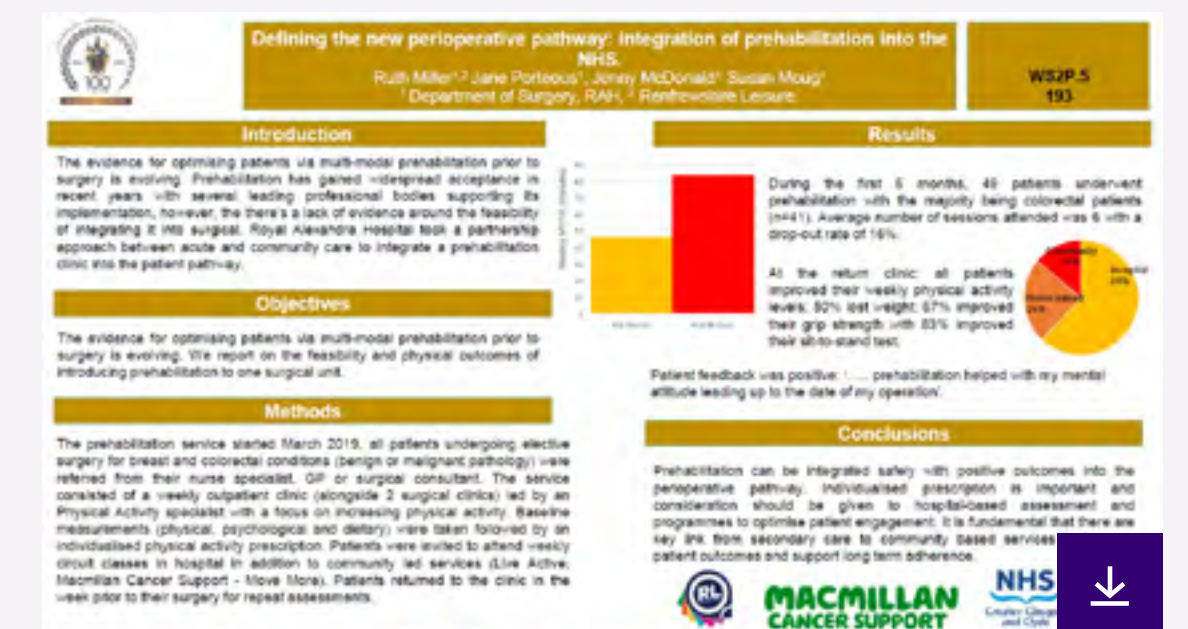


Live Active
Referral
Guidance



Consumer
Leaflet

During 2019, the Live Active programme was extended to provide prehabilitation and rehabilitation for oncology surgical patients (mainly colorectal). The team worked with a surgical unit in Royal Alexandra Hospital (RAH), Paisley. Classes were open to those referred by health professionals, but also self-referrals from patients. An overview of this work is available here:





We asked Lauren Campbell (Physical Activity Coordinator for Renfrewshire Leisure), some questions about the programme:

Please can you outline the content of the programme? Once the patient has been screened (to ensure they are a safe candidate for the class), we invite them to the circuit class in the Royal Alexandra Hospital. The class consists of a 10-15 minute warm up, progressing to a circuit style class, with cardio and strengthening exercises. To finish they have a cooldown and stretch. Classes last around 1 hour, providing personalised care, adapted to the patient's fitness level. Sessions continue until their surgery date, then, once recovered from acute care, they return for 4 weeks of rehabilitation. They are invited onto the Live Active programme after this, to continue with their exercise journey.

What impact did COVID-19 have on the programme? We had to rethink how to provide a service, without seeing patients face-to-face. We decided to create a "Renfrewshire Leisure Health and Wellbeing Team", including Live Active, Macmillan Move More, Vitality and Health Walks professionals.

We moved our classes onto Zoom, allowing patients to attend classes safely, from the comfort of their own homes. We overcame a lot of barriers to make it work, such as sound issues, how to add music to the classes, and ensuring it was a closed group (only available to screened patients). The latter was addressed by introducing a booking system with a class register. We added a password to the Zoom links (only provided to participants). When they first came onto Zoom they would be put in a virtual waiting room, giving a member of staff the opportunity to check the register.

What feedback did you obtain? All classes worked very well, and a lot of patients said it was a lifeline, and really helpful during lockdown.

What advice would you have for others interested in starting a similar programme? Consider the range of co-morbidities, which have to be taken into consideration for deciding which class level suits the person.

Case Study 3

Active Against Cancer

(Harrogate and District NHS Foundation Trust)

Active Against Cancer (AAC) is a free health and wellbeing service for people living with cancer in Harrogate. The sessions provide bespoke, individualised activity programmes, free to all people with a confirmed cancer diagnosis, regardless of current fitness level. The sessions are open to patients at all stages of the cancer journey. This includes patients who have been recently diagnosed, and are awaiting treatment (prehabilitation), those who are currently receiving treatment (maintenance), and those who have completed their treatment (rehabilitation).

Vicky Hope (Service Manager) and Kerry Archer (Programme Lead), take us through the AAC programme.

Background:

In 2018 there were an estimated 180,000 people living with Cancer in Yorkshire, with 990 new cases diagnosed per year in NHS Harrogate and Rural District CCG. There is an expanding body of evidence in support of the benefits of exercise and increased physical activity in the adult population, at every stage of the cancer journey. Exercise plays an important role in maintaining a healthy body and mind.



Harrogate and District
NHS Foundation Trust



Overview of the AAC programme

Implementation of AAC:

AAC launched in July 2019, as a pilot service with foundation funding from Yorkshire Cancer Research. For an overview to the programme, please look at the following videos



Staffing:

Patients receive an initial assessment with a specialist Physiotherapist or Physical Trainer, before working with a wider team of dedicated trainers, as part of the wider AAC team, including:

- Service manager
- Lead physiotherapist
- Lead physical trainer
- Service assistant
- A team of 10 (level 4 trained) cancer specialist physical Trainers

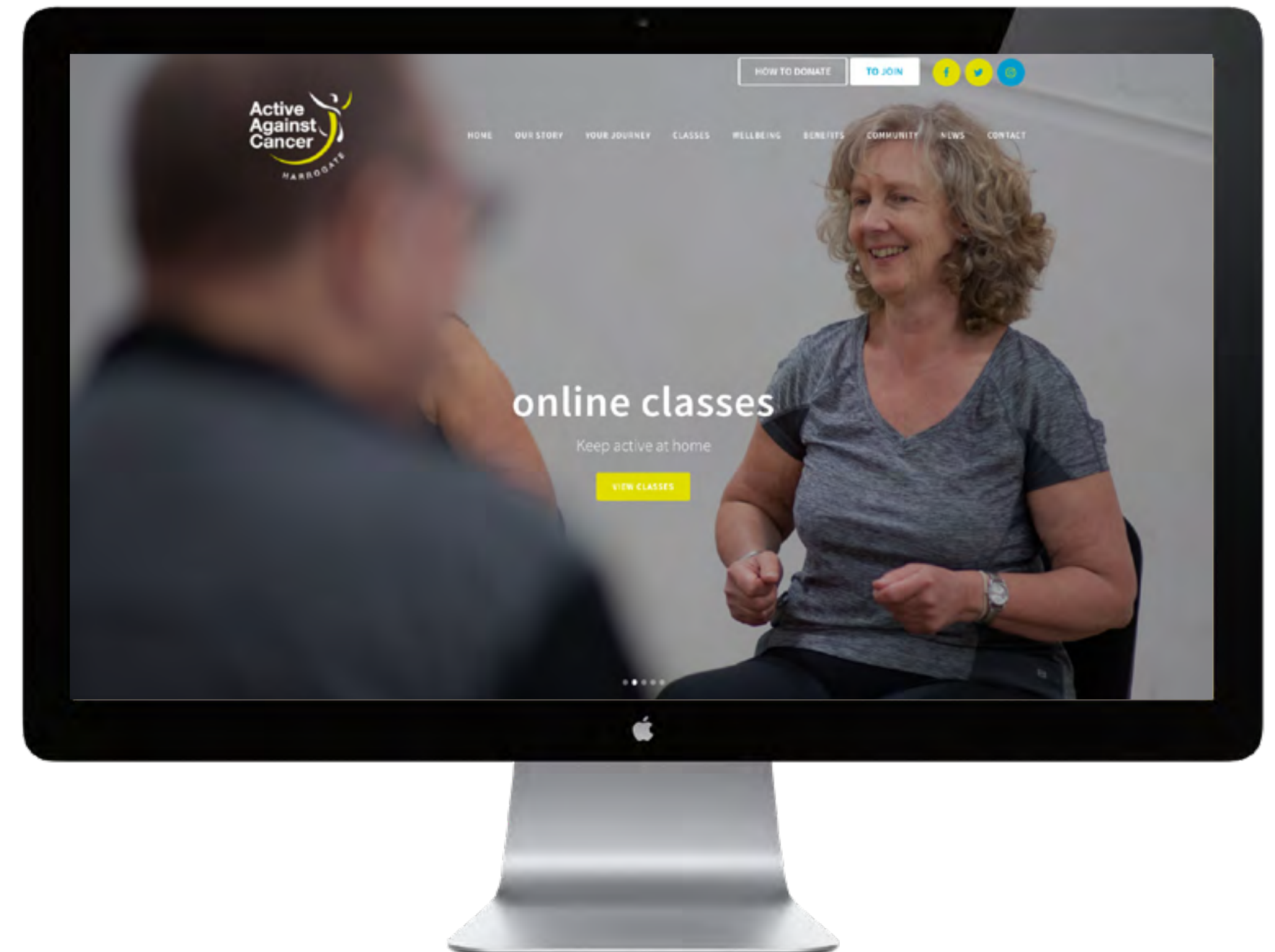
The Active Against Website provides useful resources, such as service information, and at home exercise guides:

www.activeagainstcancer.org.uk

References for publications related to the AAC:

E.Radcliffe et al. 2020. A Case Study in Perioperative Oncology Exercise Referral: The Active Against Cancer Service [Abstract]. EBPOM London. EL203.4/2.

K.Archer et al. 2020. The benefits of multidisciplinary involvement in an exercise referral service; early detection of the consequences of cancer treatment [Abstract]. Physiotherapy UK. AS-PTUK-2020_00318.



**Hear from Steve Heywood from
Active Against Cancer team**



Pathway for the programme

Referrals:

There is a well-established referral pathway with the majority of referrals made by the Clinical Nurse Specialist, but self referral is also available.

After receiving the referral, the team:

- Commit to first contact within 48 hours of receiving referral.
- Offer prehabilitation and rehabilitation classes.
- Provide links to more programmes, activity classes and gyms helping to maintain fitness for life!

Content to the programme:

AAC offers bespoke, individualised activity programmes, with a wide variety of exercise classes, activities and guidance around exercising with cancer. All activity is tailored to the individual needs of each patient, throughout their cancer journey. Classes can vary from high intensity interval training to chair based low intensity classes. Nordic walking, dancing, yoga, and pilates are also on offer.

Patients are informed that exercise forms an important part of their cancer care; in essence, activity and wellbeing is being prescribed to the patients. All assessments and the majority of classes take place at the AAC base at Harrogate Sports and Fitness Centre; however at-home programs can be provided when needed.



Pathway for the programme

Development of new resources:



Written resources:
Exercising with a PICC line



Written resources:
Introduction to exercise programme in AAC



Exercise videos:
Developed, so these can be accessed at anytime, at the individuals' convenience.



Success and achievements

Feedback:

AAC has received over 1000 referrals to date, with feedback on the programme collected from the participants:

- 4.9 / 5 for overall patient experience
- 96% 'strongly agreeing' they feel safe and well supported whilst exercising.
- Classes are designed to be engaging, fun and create a sense of community and wellbeing.
- Friendships have blossomed and support groups organically grown.
- In the two years since opening, AAC has been hugely successful in supporting patients to be physically active and make positive health choices before, during and after cancer treatment.
- The Active Against Cancer Team from Harrogate & District NHS Foundation Trust, won the NHS Parliamentary award for Excellence in Health Care for North and East Yorkshire, and was highly commended for their work at the national final in Westminster in July 2021.



NHS Parliamentary Awards

In association with
FUJIFILM
Value from Innovation

HIGHLY COMMENDED

The Excellence in Healthcare Award

Presented to

The Active Against Cancer Team
Organisation: Harrogate & District
NHS Foundation Trust

On Wednesday 7th July 2021 in Westminster

Organised by

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Case Study 4**Pilot of Enhanced Recovery for surgical Laryngeal (Head and Neck) Cancer patients**

(Belfast Health and Social Care Trust, Northern Ireland)

Support is provided from diagnosis, to patients on a referral pathway for surgical intervention of laryngeal cancer. The support continues through to the date of surgery, during post-surgical recovery, and following discharge home.

Cathy Skea (Clinical Specialist Dietitian, Royal Victoria Hospital), works with the Oncology group in Northern Ireland. Here, she takes us through the prehabilitation and rehabilitation interventions provided in the surgical laryngeal cancer patients in the acute setting at Belfast Health and Social Care Trust ('Belfast Trust').

Background to the project:

This specific patient group historically have increased length of stay in hospital, due to the nature of the disease, but also related to post-operative complications (wound breakdown), and prior treatment side effects (such as radiotherapy).

Aim of the pilot project:

To reduce complications in this patient group, and reduce length of hospital inpatient stay.





Developing the project

Previous data from the Belfast Trust Colorectal Enhanced Recovery After Surgery (ERAS) programme was used to support the case, in addition to clinical evidence from the “ESPEN guidelines – Clinical Nutrition in Surgery”¹. The pilot project was supported by the Regional Head and Neck Cancer multidisciplinary team, and Head and Neck Surgical and Anaesthetic teams.

The Multidisciplinary team (MDT)

Which professionals work in the MDT?

- Cathy Skea - Clinical Lead Dietitian, Head and Neck Surgery
- Andrea Thomson/ Melanie Ardis – Clinical Nurse Specialist (CNS), Head and Neck Surgery
- Gillian Gray/ Barry Devlin - Consultant Head and Neck Surgeon

What are the roles of the MDT?

To identify and assess all patients undergoing Total Laryngectomy Surgery for laryngeal cancer, in Belfast Trust. The early identification of Head and Neck cancer patients, aims to reduce post-operative complications, and length of stay in hospital.

These are the main principles of Enhanced Recovery after Surgery (ERAS): supporting and optimising nutritional intake before, during, and after surgery, with minimal fasting periods. Education, alongside written information, is provided to patients, outlining the surgical intervention, and the role of nutritional support, with the aim of returning to normal activities as soon as possible post-operatively.

Nutritional interventions

Referrals for the dietitians:

Referred directly from the Head and Neck Consultants, and the ENT (Ear, Nose, Throat) Consultants. After this, patients can be seen by the dietitians in outpatient face-to-face appointments, via virtual or telephone appointments, and during their admission to the hospital. Talking (speech) communication can be difficult in this patient group, due to communication difficulties (from the location of the cancer in the larynx). Texting over mobile phones, virtual, or face to face appointments addresses these issues.

- Appointments include individualised assessments and nutritional screening, completed by the CNS and dietitian - This screening assesses weight loss,
- Body Mass Index (BMI), grip strength, with baseline measurements recorded, and weekly follow-up, until the date of surgery. If intake is limited, caused by a difficulty in swallowing food and/or drink (dysphagia), the patient can be admitted to hospital earlier for specialist support, to maximise nutritional intake prior to surgery.

During the inpatient stay, the ERAS programme is initiated:

Referred directly from the Head and Neck Consultants, and the ENT (Ear, Nose, Throat) Consultants. After this, patients can be seen by the dietitians in outpatient face-to-face appointments, via virtual or telephone appointments, and during their admission to the hospital. Talking (speech) communication can be difficult in this patient group, due to communication difficulties (from the location of the cancer in the larynx). Texting over mobile phones, virtual, or face to face appointments addresses these issues.

- Before surgery, patients receive specialist nutrition products, to provide a source of carbohydrate (sugars). This prevents a prolonged time as 'nil by mouth' (no food or fluids) prior to surgery. People with a known history of diabetes do not receive this stage of the intervention.
- After surgery, all patients receive early support with their nutritional intake, establishing intake by day 5 after surgery.



Funding for the project

This is currently an ongoing pilot project, for the laryngectomy patient population. Funding already existed for the service (including CNS and dietetic lead). Additional funding was provided internally by the Trust, after Cathy was successful in submitting a bid for urgent dietetic staffing support in this patient group (highlighted through risk management processes). This additional money was provided on a temporary basis during the pilot, recruiting a part-time (0.5 of whole time equivalent) Band 6 Dietitian, supporting Cathy (the dietetic lead for this patient group). The data collected is being used to develop a case for ongoing (permanent) funding of the Head and Neck cancer dietetic team (Dietetic Lead and Band 6).

Data gathered during the pilot

Ongoing audit is being provided of this service (for patients under the ERAS protocol). 16 patients are included in the initial data collection:

- The mean Length of stay (LOS) reduced by 2-3 days.
- A reduction in post-operative issues, such as fistula formation, appears to be supported by the ERAS interventions, but more data is required.
 - » Patients with prior radiotherapy, requiring further salvage surgery, are excluded from the pilot data. The delayed healing of these patients, means that feeding will often not commence until day 10+ (versus other patients, with feeding initiated by Day 5). However, all other parameters are kept the same.

Reflections from Cathy Skea, on the current pilot project

We feel there was adequate engagement with the clinical teams prior to initiating the project, and there were not many issues encountered during the implementation stage. We have implemented patient satisfaction questionnaires, to support further improvements.

We do however, require more investment into staffing groups (Physiotherapy and Dietetics), to be able to continue the project - Future plans would be to develop this into all Head and Neck surgeries, such as neck dissection, and develop further patient literature.

Overall, by working within the MDT, there was a development of skills across the team (clinical, managerial and service development), providing good job satisfaction, and promoting career development / progression. There have also been good outcomes for patients, while saving money to an ever-stretched NHS budget. The data was presented to the regional Northern Ireland Multidisciplinary meeting, with good feedback.



“

Cathy's final tips for those starting a similar project.

“Have a small key objective to start with, don't aim to do it all at once, as with small steps the project is more likely to succeed. You will then feel satisfied that you have achieved your objective. Keep at it, and work as a team!”

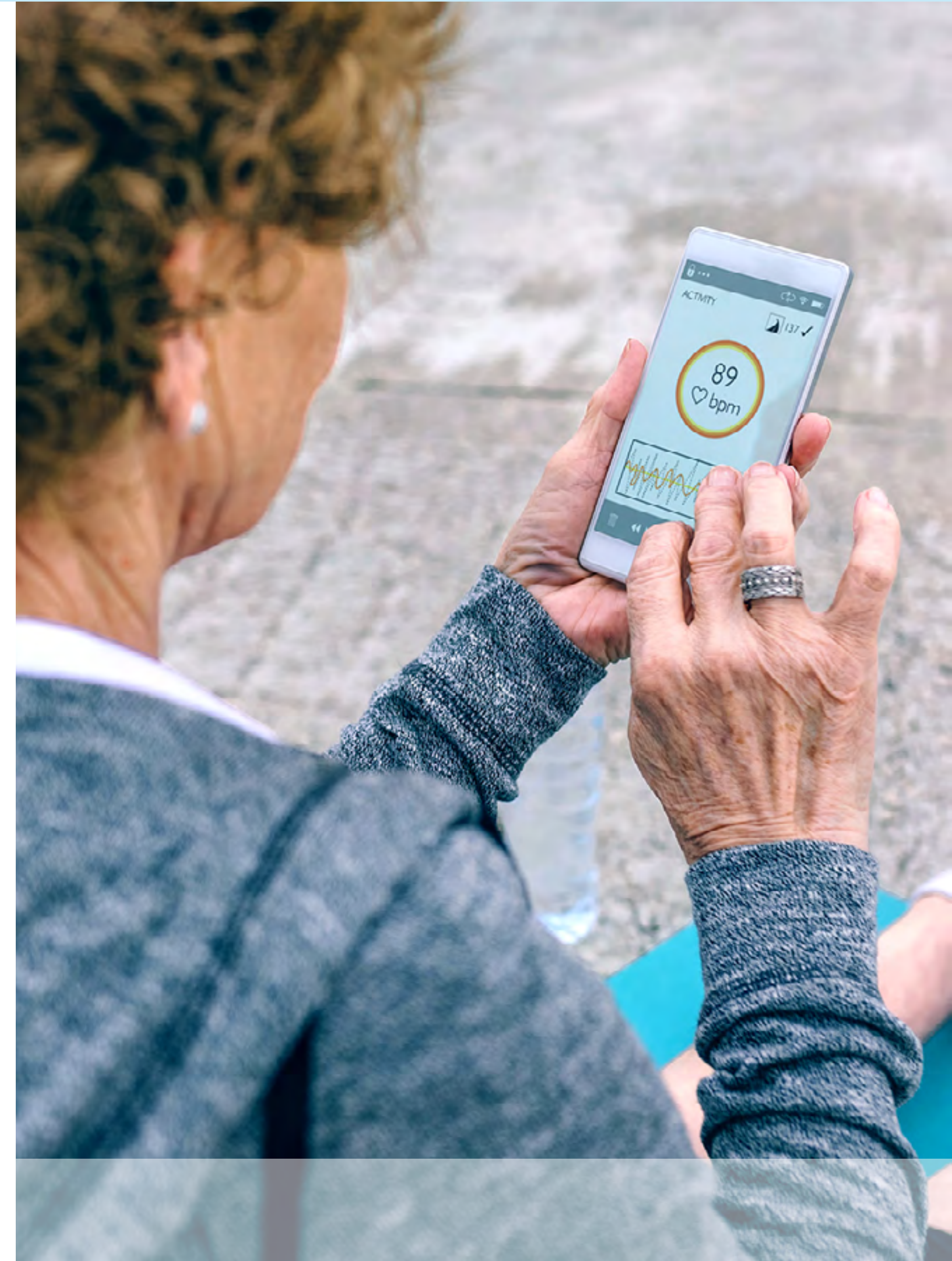
Case Study 5

Prehabilitation & Rehabilitation Neuro-oncology multidisciplinary project in Velindre Cancer Centre

A prehabilitation neuro-oncology clinic is provided in Velindre Cancer Centre (VCC), Cardiff, Wales. This is delivered by Allied Healthcare Professionals (AHPs), and a Clinical Nurse Specialist (CNS), to patients with primary brain tumours. Siobhan Pearce, Macmillan Interim Deputy Head of Therapies, and Cathryn Lewis, Project Lead & Macmillan Clinical Lead Occupational Therapist, outline this project.

This was a fixed term project, providing a rapid access service, for Neuro-oncology patients attending VCC, with:

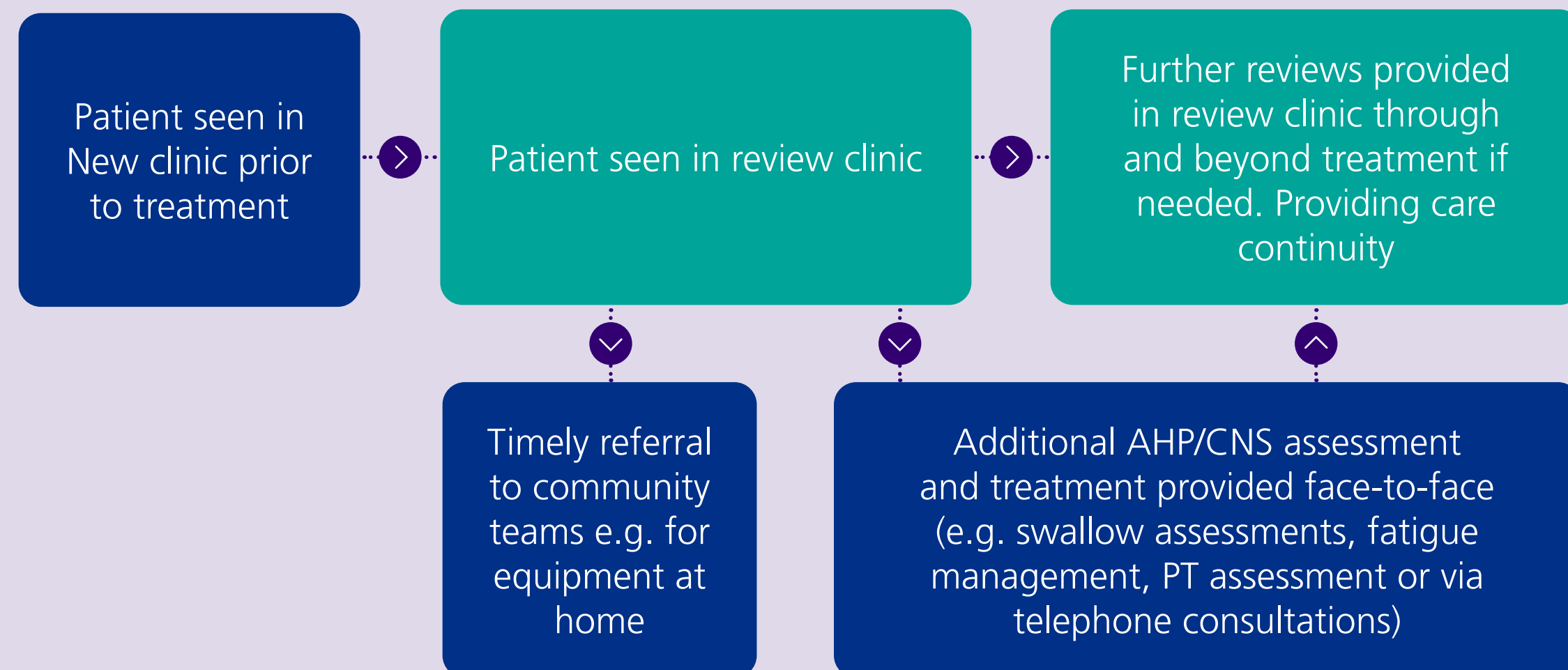
- An initial virtual consultation in the new patient clinic, before the patient starts anti-cancer treatment.
- During the initial appointment (screening), if the patient requires ongoing intervention from 2 or more of the MDT team, they are booked into the Review clinic.
- The number of Review appointments are tailored to the individual, providing **targeted or specialist intervention**, with the appropriate health professional(s) providing interventions in the same clinic (to limit repeated appointments).
- Additional appointments are booked with wider health services (such as psychiatric / counselling support).



The reformed pathway and joint working in practice:

- A 60 year old lady, diagnosed with an inoperable, incurable brain stem glioma.
- Issues with swallowing, speech, nutritional status and mobility, were identified by the AHP's and CNS early in the pathway.

Post transformational bid



Targeted therapy:

Received additional appointments, outside of the review clinic setting:

- As she was at severe risk of aspiration (food and drink entering her lungs), and malnutrition (with reduced food intake), the SLT and DT worked with the patient to support her nutritional intake. A nasogastric tube was inserted to provide nutrition and hydration during radiotherapy treatment.
- PT and OT supported safety and independence within the home environment.
- Due to psychological issues, a referral to psychological services was provided.

Reflection:

Received additional appointments, outside of the review clinic setting:

- The cohesive MDT approach ensured the patient successfully completed treatment at VCC, without complications. She remained at home, within her preferred environment, with no inpatient admissions. Self-management with proactive information, advice, and interventions are central to this clinic, helping to prevent crisis point management, and enhance patient-centred care.

Staffing model for the Multidisciplinary Team (MDT)

Neuro-oncology patients have complex and holistic needs, with national guidelines recommending a cohesive and coordinated approach, with the MDT available to anticipate, ameliorate, and treat complex and rapidly changing symptoms (NICE 2018).

The project received fixed-term funding for staffing over 19 months, providing a new and a review patient clinic each week. The following health professionals attend this clinic:

- 0.2 WTE Band 6 Occupational Therapist
- 0.2 WTE Band 6 Dietitian
- 0.2 WTE Band 6 Speech and Language Therapist
- 0.2 WTE Band 6 Physiotherapist
- 0.2 WTE Band 6 Clinical Nurse Specialist

Virtual working

- The MDT developed a virtual pathway, this ensured a sustainable and safe means of service delivery during the COVID-19 pandemic. The service:
- Provided a joint-clinic model online, reducing the number of hospital appointments, and repetition in treatment discussions
- Avoided travel from home: particularly beneficial for this patient cohort, often experiencing significant fatigue, with complex neurological deficits
- Provided a sustainable and safe service delivery model during the pandemic



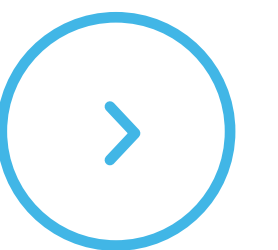


Section 3: Design

Designing and implementing your own project

The following main themes are included, linked to supporting projects within personalised care, prehabilitation and/or rehabilitation in cancer care:

- Explanation and role of outcome measures
- Outline of data collection processes
- Linking the above information into funding processes – developing a business case
- Engaging with stakeholders (key individuals and groups)
- Examples of existing projects, and how funding was achieved, are provided across the different nations in the
- Using data gathered for funding processes / calculations: Cost Consequences Calculator
- Promoting the project



Data collection

- Collection of the minimum dataset (MDS) should be mandatory. Work by the Transforming Cancer Services Team in London recommended an MDS for cancer rehabilitation which could also be used for prehabilitation. (healthy london. org & Macmillan Cancer Support, 2017)

The MDS is outlined in the following table:

Category	Data field
Demographics	<ul style="list-style-type: none">• Age• Sex• Ethnicity
Cancer history	<ul style="list-style-type: none">• Cancer type• Date of diagnosis• Cancer treatment• Stage of treatment
Provider	<ul style="list-style-type: none">• Date form completed• Name of provider• Provider type• Setting
Therapy	<ul style="list-style-type: none">• Reason for prehabilitation / rehabilitation• Treatment received• Details of any other non-cancer related prehabilitation / rehabilitation for another issue.• Number of visits/virtual sessions - one to one and group• Discharge Status

Outcome measures

In addition to the MDS, the correct outcome data is able to support your case for implementing or sustaining the project. This needs to work across the service, but also establish what will support those living with cancer.

References Available at: <https://euroqol.org/support/how-to-obtain-eq-5d/>

1. NHS England » Module 1: Patient Activation Measure – implementation quick guide

2. EORTC -QLQ C30 “<https://qol.eortc.org/>” EORTC Quality of Life Website - EORTC - Quality of Life : EORTC – Quality of Life

3. Self-efficacy for self management of chronic disease (Lorig) “https://www.selfmanagementresource.com/docs/pdfs/English_-_self-efficacy_for_managing_chronic_disease_6-item.pdf” Microsoft Word - sec6.docx (selfmanagementresource.com)

4. National Cancer Quality of Life Survey“https://www.cancerqol.england.nhs.uk/about_the_survey/index.html#:~:text=About%20the%20Survey%20The%20Cancer%20Quality%20of%20Life,in%20England%20who%20have%20been%20diagnosed%20with%20cancer.”Cancer Quality of Life Survey - About the Survey (england.nhs.uk)

5. Sit to Stand Simmonds, M. (2002). Physical Function in Patients with Cancer: Psychometric Characteristics and Clinical Usefulness of a Physical Performance Test Battery. Journal Pain and Symptom Management, 24, 404–414

6. Timed up and go test“https://www.ons.org/sites/default/files/TUG_Test-a.pdf” The Timed Up and Go (TUG) Test (ons.org) Gabrielson, D.K. (2013) Use of an Abridged Scored Patient-Generated Subjective Global Assessment (abPG-SGA) as a Nutritional Screening Tool for Cancer Patients in an Outpatient Setting. Nutrition and cancer. Vol.65, Issue

7. Dukes Activity Status Index (DASI) Hlatky, M. A. et al. A brief self-administered questionnaire to determine functional capacity (The Duke Activity Status Index). (1989) Am. J. Cardiol. 64, 651–654.

8. Degree of health e.g., effective management of symptoms and side effects“<https://connect.ichom.org/standard-sets/breast-cancer/>” Breast Cancer – ICHOM Connect and HYPERLINK “<https://connect.ichom.org/standard-sets/colorectal-cancer/>” Colorectal Cancer – ICHOM Connect

9. Days alive and out of hospital Myles PS, Shulman MA, Heritier S, et al. (2017) Validation of days at home as an outcome measure after surgery: a prospective cohort study in Australia. BMJ Open :e015828. doi:10.1136/bmjopen-2017-015828 Patient Generated Subjective Global Assessment PG-SGA® | Pt-Global. <https://pt-global.org/pt-global/>.

The following table outlines examples of outcome measures that could be used:

Outcome measure category	Suggestions/examples of outcome measures to be used
Quality of life measures	Patient Activation Measure (PAM) ¹ EQ-5D-5L,EORTC-QLQ C30 ² Self-efficacy for self-management of chronic disease (Lorig) ³ <ul style="list-style-type: none">• The above measures could be collected alongside review of the National Cancer Quality of Life Survey results.⁴
Functional measures	Sit to stand ⁵ , Timed up and go test ⁶ Dukes Activity Status Index (DASI) ⁷ Nutrition Assessment using Patient generated Subjective Global Assessment (PG-SGA)
Health economic data	Return on investment, cost benefits
Degree of health/Disutility of care measures	Degree of health e.g., effective management of symptoms and side effects ⁸ Days alive and out of hospital at 90 days ⁹

Implementing person-centred outcome measurement tools

Scottish Government outlined the importance of Realistic Medicine, as “people are more likely to have greater confidence in decisions reached and less likely to regret their treatment choices. So good communication, listening to people, displaying empathy and asking the right questions all lie at the heart of practising **Realistic Medicine**”

Implementing a person-centred outcome measurement tool, can provide the opportunity to ask the appropriate questions, to empower and engage the person in the planning their own care.

Outcome measures for the individual: Case study in St Francis' Hospice using subjective goal setting, through the GAS-Light Tool which is provided on the next page. This includes improvements made when patients are engaged in the outcomes recorded.



Outcomes Case Study

Using the GAS Light Rehabilitation Outcomes measurement tool with inpatients in St Francis' Hospice

(Berkhamsted, East of England)

Manisha Cook, Specialist Palliative Care Physiotherapist, explains the services provided at St Francis' Hospice. She also provides an example of how the Gas Light outcomes measurement tool has been used for goal planning, in a patient with kidney cancer

We asked Manisha some questions about the services provided:

Which staff work in the Wellbeing therapy team?

"We have PT, OT, Art Therapists, and Complementary Therapists working in the team – they have time benchmarked within job specifications, and the service development plan, for palliative rehabilitation. Their main roles are offering inpatient, community and outpatient services."

What support and services do you offer to patients?

"We offer a wide range of rehabilitation services, from a fantastic Wellbeing Therapy Team:

- Offer early support for cancer treatment
- Provide **specialist cancer rehabilitation training** (Pinc and Steele)
- OT- service runs vocational rehabilitation HOPE courses
- Complementary therapy service
- Psychological adult and children's services (pre and post bereavement)
- Carers services



Setting a personalised care plan with outcome measures

Patient “C” was admitted as an inpatient to St Francis’ Hospice, for rehabilitation support, to increase mobility and independence with daily living tasks. Click on the tabs below to learn more about their rehabilitation.

Background (Medical, Social)

Patient “C” - 54 year old female patient

Medical:

Kidney cancer, with metastasis.
Lymphoedema, Leg ulcers reducing mobility, alongside cancer related fatigue.

Baseline physical activity level:

Mobilising with crutches, managing the stairs at home.

Current physical activity level:

Required assistance of 1-2 people to move into and out of bed.

Social:

Lives at home with her husband, with bedroom and bathroom upstairs.



Personalised Care Goal Setting in Patient “C” – “what matters to me?”

- Likes to be independent as possible
- Daughter getting married in a few weeks, and would like to attend the wedding
- Motivated to improve her functional status



Outcome measures

Outcome measures are collected using the GAS (Goal Attainment Scaling in Rehabilitation)

Light tool: [King's College London - GAS - Goal Attainment Scaling in Rehabilitation \(kcl.ac.uk\)](https://www.kcl.ac.uk/gas)

St Francis’ Hospice funded 2 staff to attend the training on outcome tool – to implement into rehabilitation services

Recording Outcome Measures

The following paperwork was completed during the inpatient stay, using the GAS Light tool.

D9

Surname

Case Study 2

Age

54

Firstname

Gender

F

ID code (e.g NHS Hospital Number)

Date goal set

17/09/19

Diagnosis

Kidney CA

Date goal achieved

24/09/19

1 = Important

1 = doubtful

2 = Very important

2 = possible

3 = Extremely important

3 = probable

Some function = -1

No function = -2

A lot more achieved = 2

A little more achieved = 1

Achieved as expected = 0

Partially achieved = -1

Unchanged = baseline score

Worse = -2

Goals	Baseline description	Patient Goals	SMART Goals	Importance	Probability	Weight	WSq	Baseline	W x base	Achieved						
1	Mobility	To improve mobility and mobilise with crutches	To attend her daughters wedding on the 27/09/19 mobilising short distances with crutches	3	2	2	4	-1	-2	2						
2		To be able to manage at home as independently as possible	To manage daily ADLs at home such as mobilising on stairs independently	2	2	2	4	-1	-2	1						
3						0	0		0							
						SumW	4	16								
						Sum (WSq)		8								
						Factor	10.4									
						Sqrfactor	3.2									
						GAS calculation		<table><thead><tr><th>Baseline</th><th>Achieved</th><th>Change</th></tr></thead><tbody><tr><td>37.6</td><td>68.6</td><td>31.0</td></tr></tbody></table>			Baseline	Achieved	Change	37.6	68.6	31.0
Baseline	Achieved	Change														
37.6	68.6	31.0														

Print and Save

Name of patient

Date: _____

	Goals	Initial date	Review date			
1	To improve mobility and mobilise with crutches					
2	To be able to manage at home as independently as possible					
3						



What's important to me is: Attending my daughters wedding

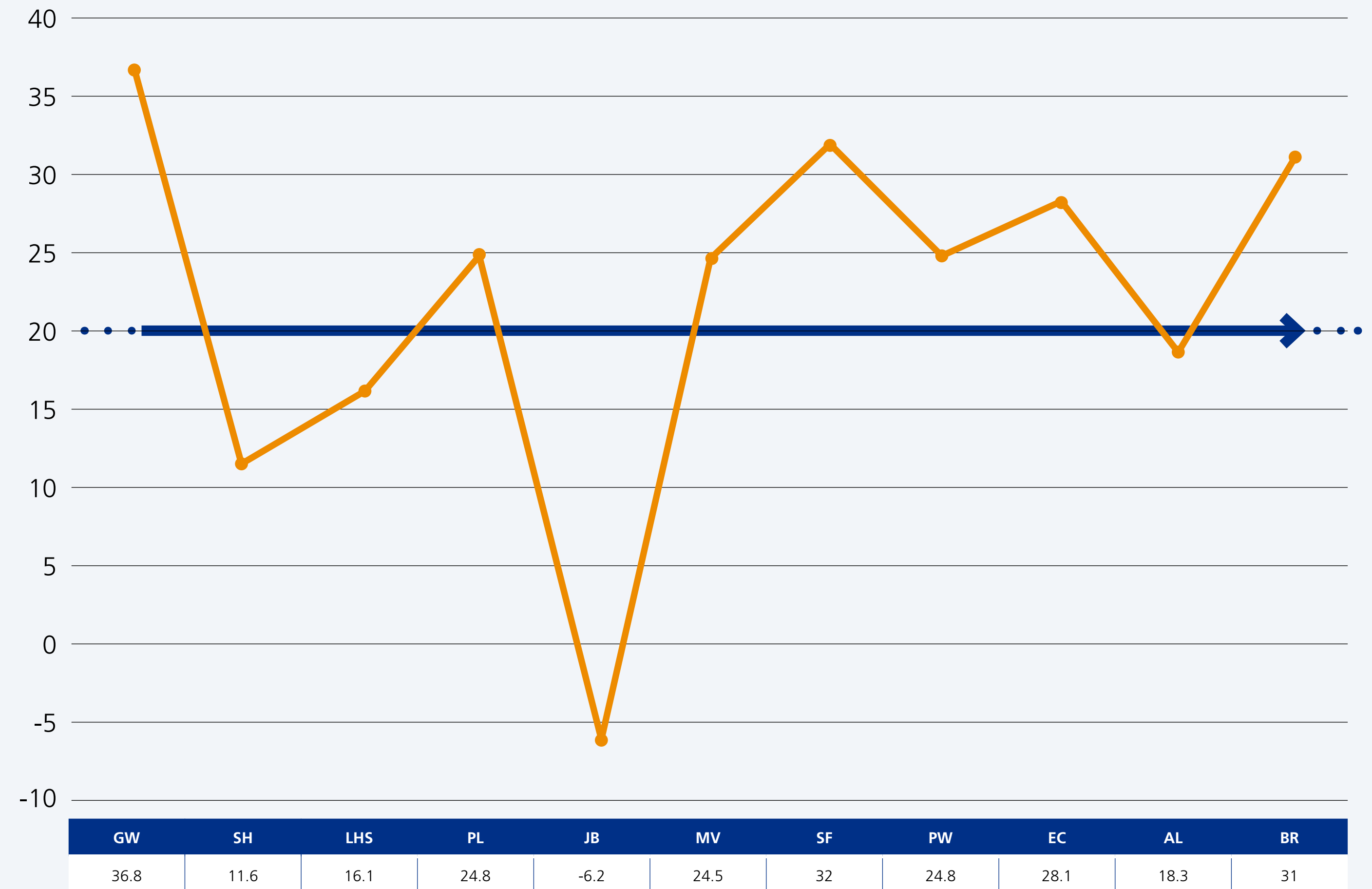
Assessing data – data collection across several patients in St Francis; Hospice

A change score of 20 or more is deemed to be statistically significant.

Remember to record the reasons for improvement and deterioration – why did we meet / not meet these goals?

- Consider – what can we use this data for?
- Consider – how many staff need to be trained in this Outcome collection tool? (in this case – GAS Light Outcomes Tool)

GAS goals change score





Key performance indicators

These are used in addition to outcome measures, to evaluate performance. Local agreement is needed on what performance measures to use. A selection are shown below:

- Patient experience/satisfaction questionnaires: Friends & Family Test
- Transforming cancer services Team in London Cancer Rehabilitation service improvement tools (<https://www.healthylondon.org/resource/cancer-rehabilitation-pathways-service-improvement-tools/>)¹
- Length of stay
- Post-operative complications
- GP visits for issues pre and post treatment
- Waiting times met and improvements demonstrated.
- Survival and disease control

Role of implementing locally defined outcomes

It is anticipated the following outcomes will be achieved, through the funding of personalised care, prehabilitation and rehabilitation services, for people with cancer:

- Improve the ability of people living with cancer to self-manage
- Improve the quality of life and function of people living with cancer
- Improve patient experience
- Improved cardiorespiratory fitness
- Improved nutritional status
- Improved aspects of neuro-cognitive function
- Providing a teachable moment to promote healthy behaviours, enhancing recovery following treatment
- Reducing post treatment complications
- Reducing length of stay in hospital and use of associated services such as acute oncology, accident and emergency, GP out of hours services and wider health and social care services.
- Improve the levels of knowledge of the wider workforce around patient support and management





Considerations for the chosen outcome tool

Administration method (time, equipment, location, specialty / number of staff)

Ease of use (inputting data & data analysis)

Approval from key stakeholders to implement

Frequency of review

Recording and storage of data

Cost (equipment / license fees / training on its use)

Copyright to use programmes

Copied from NHS Digital (2021)¹:

Developing projects: Planning and Business case development

Examples of case studies are provided below, on using data collection, and outcome measures, in practice:



**Outcome measures and data collection:
Prehab4Cancer in Greater Manchester**



**Outcome measure benchmarking, and funding
route planning: Prehabilitation & Rehabilitation
project in Velindre Cancer Centre: Sustainable
Funding and Outcome Measures**



**Outcome measures for service level review:
A case in Lung cancer services at Barts
Health, using objective measures through
the EQ-5D-5L**

Prehab4Cancer (Greater Manchester)

Prehab4Cancer evolved from the surgical pathway, Enhanced Recovery After Surgery (ERAS). This was a pre- and post-surgical care pathway already running in Greater Manchester, aiming to reduce pulmonary complications (the most common significant complication after major surgery).

Zoe Merchant (Highly Specialist Occupational Therapist, Programme Lead Prehab4Cancer and Recovery Programme), outlines the content of this programme.

Please click on the following link for the background and introduction to patient groups enrolled onto the programme:

Watch video



Referrals onto the programme:

Referrals are provided by online referral forms (from health professionals). The inclusion criteria was embedded into the pathways, showcasing the programme, and support provided to patients. Zoe Merchant explains this process here:

Watch video



...definitely a lot better

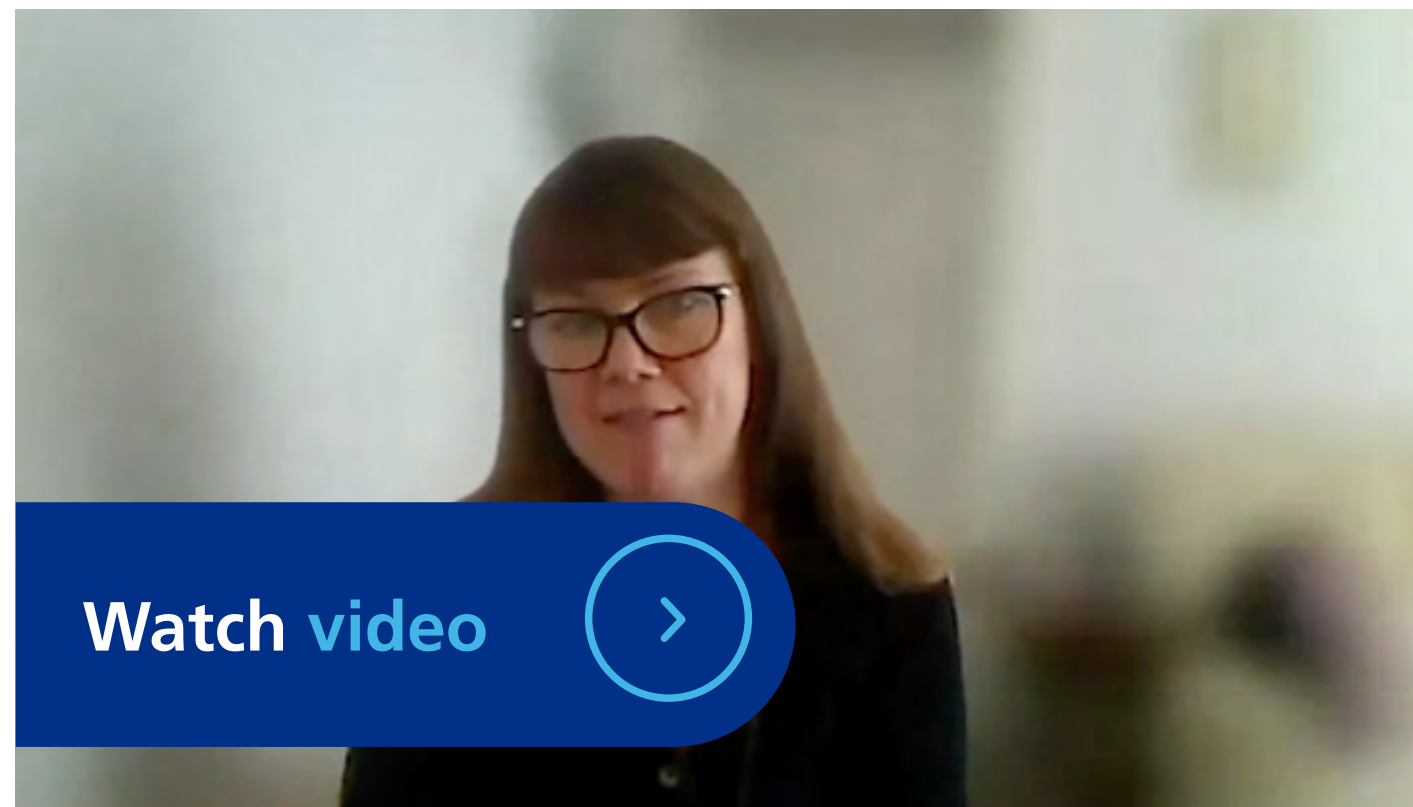


Content included in the programme

- Individualised advice is provided, based on the persons functional age, rather than chronological age.
- Patient and family education about the ERAS pathway is provided, facilitated through the 'Surgery School' programme. This includes Inviting patients, and significant others, to a 90 minute facilitated multidisciplinary education session, prior to the surgery.
 - » Pre-operative cardiovascular exercise, and muscle strengthening
 - » smoking cessation,
 - » medical optimisation
 - » post-operative pain management ICOUGH, outlining aims of early mobilisation
 - » good oral healthcare
 - » incentive spirometers
 - » Outlining the role of early fluids and nutrition
- Promote reassurance and normalisation of the process they are going through: open up visits to the inpatient areas where the person will be after surgery (e.g. High Dependency Unit)

Stakeholder engagement

Zoe Merchant outlines the engagement with key stakeholders, and the subsequent workforce development, in the following video:



Guidance in maintaining engagement with key stakeholders:

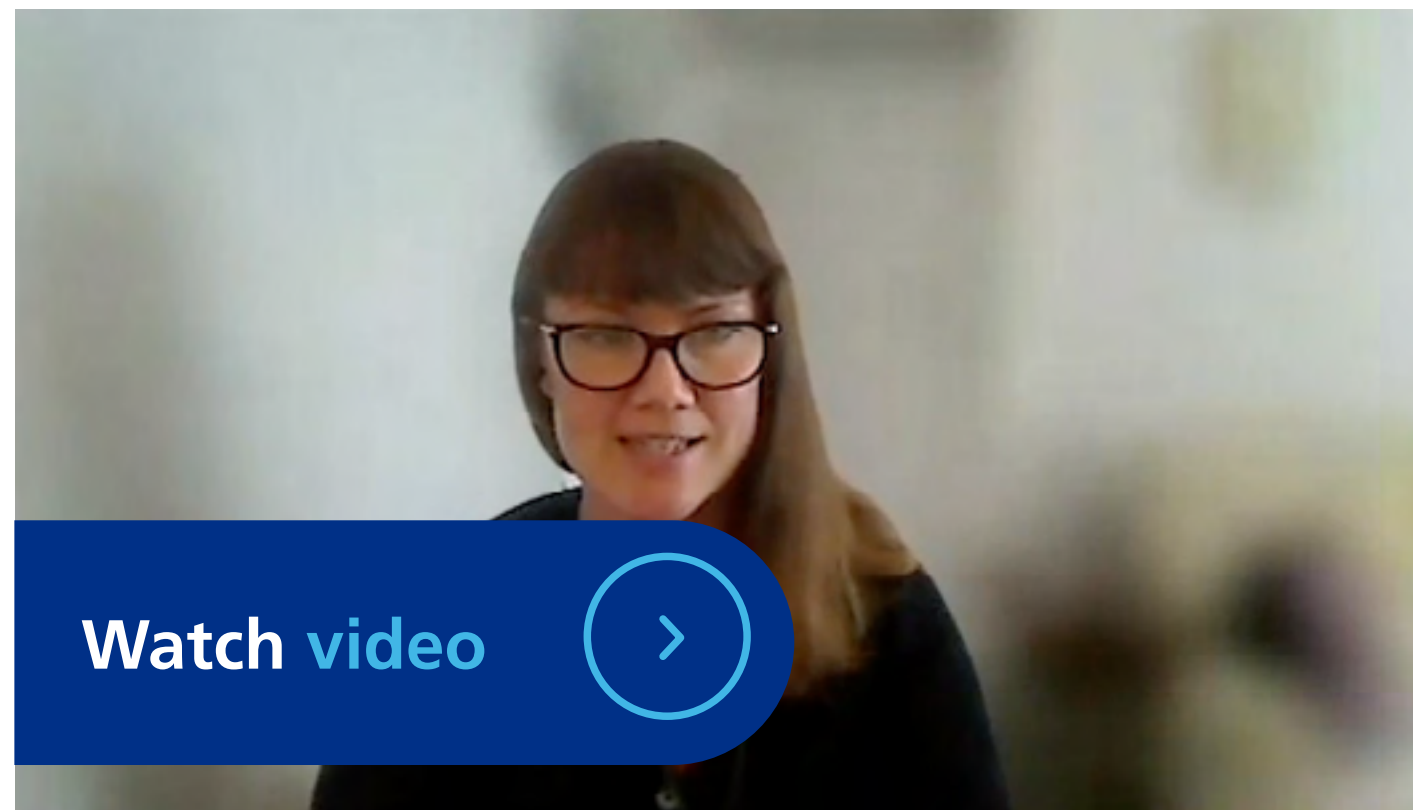
- Monthly meetings: Chaired by a clinical lead (surgeon or physician) and supported by the 'Prehab4Cancer' programme and clinical leads.
- These subgroups informed the co-design and effective implementation of the programme
- Accounting for specific factors in the programme delivery relative to tumour group
- Ensuring consistent communication to patients and family members
- Promoting ownership of the programme from subgroups – "critical to the success of the programme delivery"

The project team managing the delivery of Prehab4Cancer programme, includes:

- Secondary healthcare clinical lead (anaesthetic and critical care with specialist experience in peri-operative medicine)
- Primary Care Lead (Macmillan GP)
- Greater Manchester Cancer programme lead (Specialist Occupational Therapist with a background in complex rehabilitation and community NHS service leadership)
- Greater Manchester Active programme manager (former CAN-Move Manager)

Funding

This programme was supported and funded by a Health Foundation Scaling up Improvement grant (2018-2020). Zoe Merchant takes us through the funding processes, timeframes and design processes in the enclosed video:



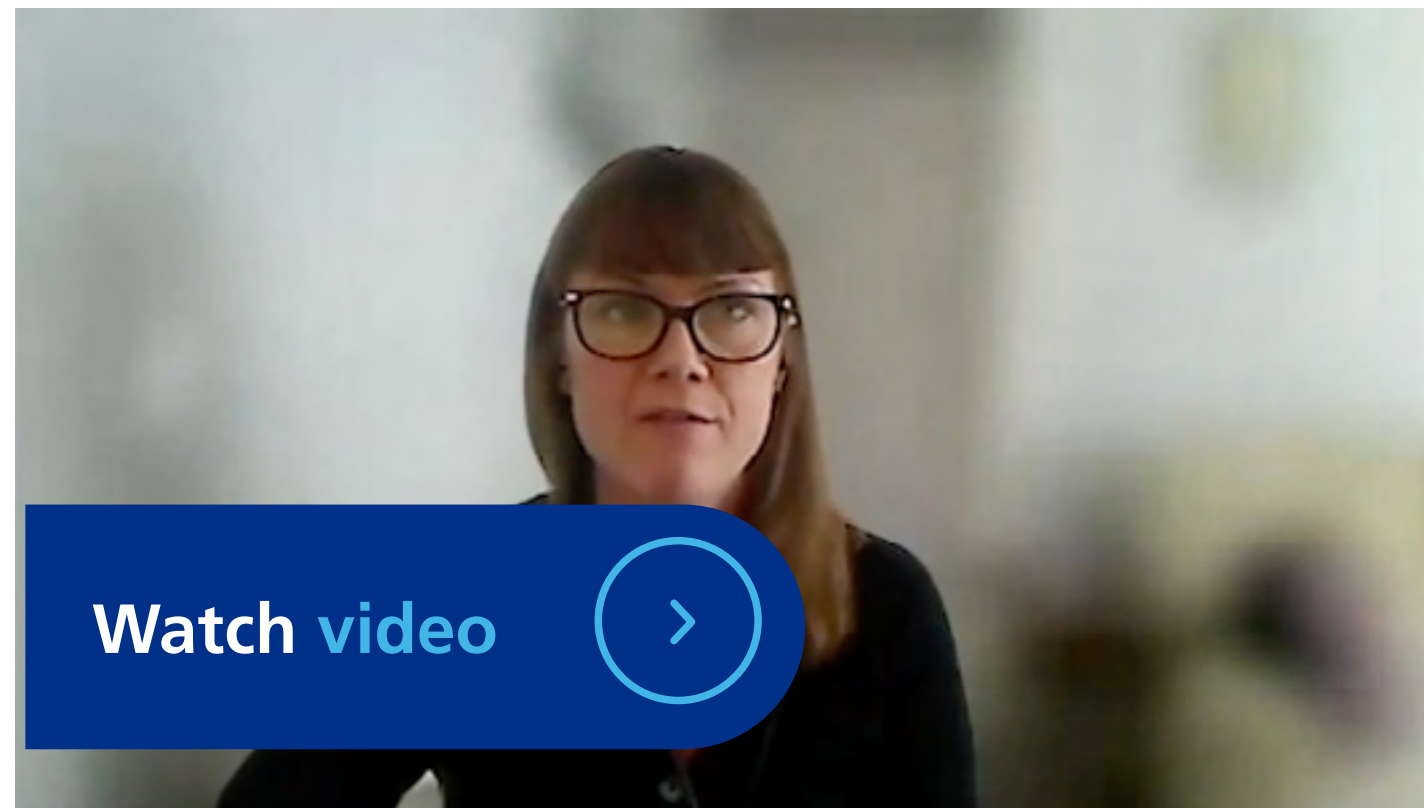
Investment into training for staff:

- Training was provided to staff involved in delivering the programme, to upskill in the relevant clinical skills, and to allow further development of the programme in the different teams. This included:
- All GM Active fitness instructors trained in: SAGE and Thyme communication skills, nutritional screening (devised by cancer specialist dietitian members of the AHP Advisory Board), exercise prescription, and prehabilitation overview.
- Facilitated reflective peer sessions with oncology specialist psychologist and programme lead
- Weekly education sessions - such as enduring mental health conditions

Collection of data outlined the success of the ERAS + platform in Manchester Royal Infirmary Hospital, supporting adoption of the programme by the GMHSCP system. This meant the programme was implemented into a further six NHS hospital trust sites within the GM region.

Prehab4Cancer Outcome Measures

Zoe Merchant takes us through the data collection and outcome measurements here:



Since the launch date in April 2019, some key data was collected on the programme. The enrolment of over 600 patients from across the GM region, included:

- Colorectal (n: 331) average age 67 (47% over the age of 70), 60% are male
- Lung (n: 258) average age 69 (57% over the age of 70), 47% male
- Approximately 80% of people referred agree to attend their initial assessment and 95% of those attending this appointment engage in the programme

Focus groups were held at 6 months to gather initial participant feedback, generating consistently positive support for Prehab4Cancer.

A summary of the programme and data can be found in the following publication:



Prehabilitation & Rehabilitation project in Velindre Cancer Centre: Sustainable Funding and Outcome Measures

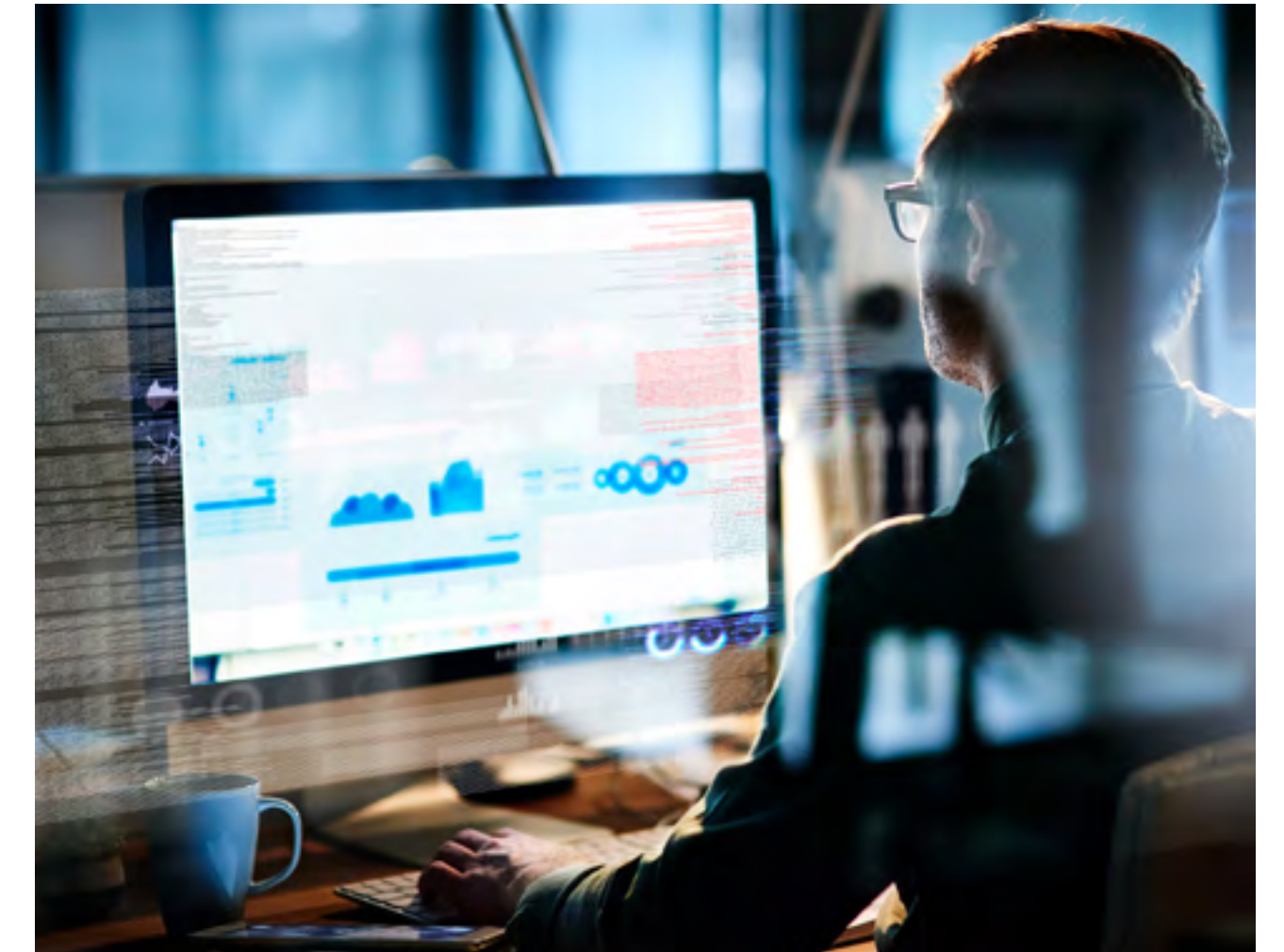
The Velindre Cancer Centre (VCC) neuro-oncology MDT clinic was developed after extensive benchmarking, aiming to deliver patient-centred, gold-standard care. Siobhan Pearce, Macmillan Interim Deputy Head of Therapies, and Cathryn Lewis, Project Lead & Macmillan Clinical Lead Occupational Therapist, provide us with further information on this project.

Aim of the MDT clinics:

Provide a cohesive neuro-oncology MDT clinic, meeting the holistic needs of patients with brain tumours, attending VCC.

Key objectives of the MDT clinics:

- Provide timely and cohesive MDT assessment, at all points of the neuro-oncology patient pathway
- Capture quantitative and qualitative data relating to interventions provided
- Capture staff satisfaction scores (wider team, and key stakeholders for the integrated model of care)
- Capture Patient Reported Experience Measures (PREMS)
- Capture Patient Reported Outcome Measures (PROMS)
- Thoroughly evaluate and evidence cost savings
- Promote the work within VCC and beyond



Handy hint!

This is useful to outline:

- ✓ Using government funding to pilot a project
- ✓ Involving a multi-disciplinary approach
- ✓ Pathway development for neuro-oncology patients

Funding & clinic development pathway

In May 2020, a bid was approved by the Welsh Government's Planned Care Programme Outpatient Transformational fund, allocating hours for AHPs and CNS to deliver a clinic, at any point along the patient's cancer journey (pre-treatment, treatment, recovery or end of life care). Without this initial investment the project would not have been possible.



Funding provided from July 2020 - March 2021 (8 months)



Reconfigured existing service with a joint AHP clinic: Occupational Therapist, Speech and Language Therapist, and the CNS.



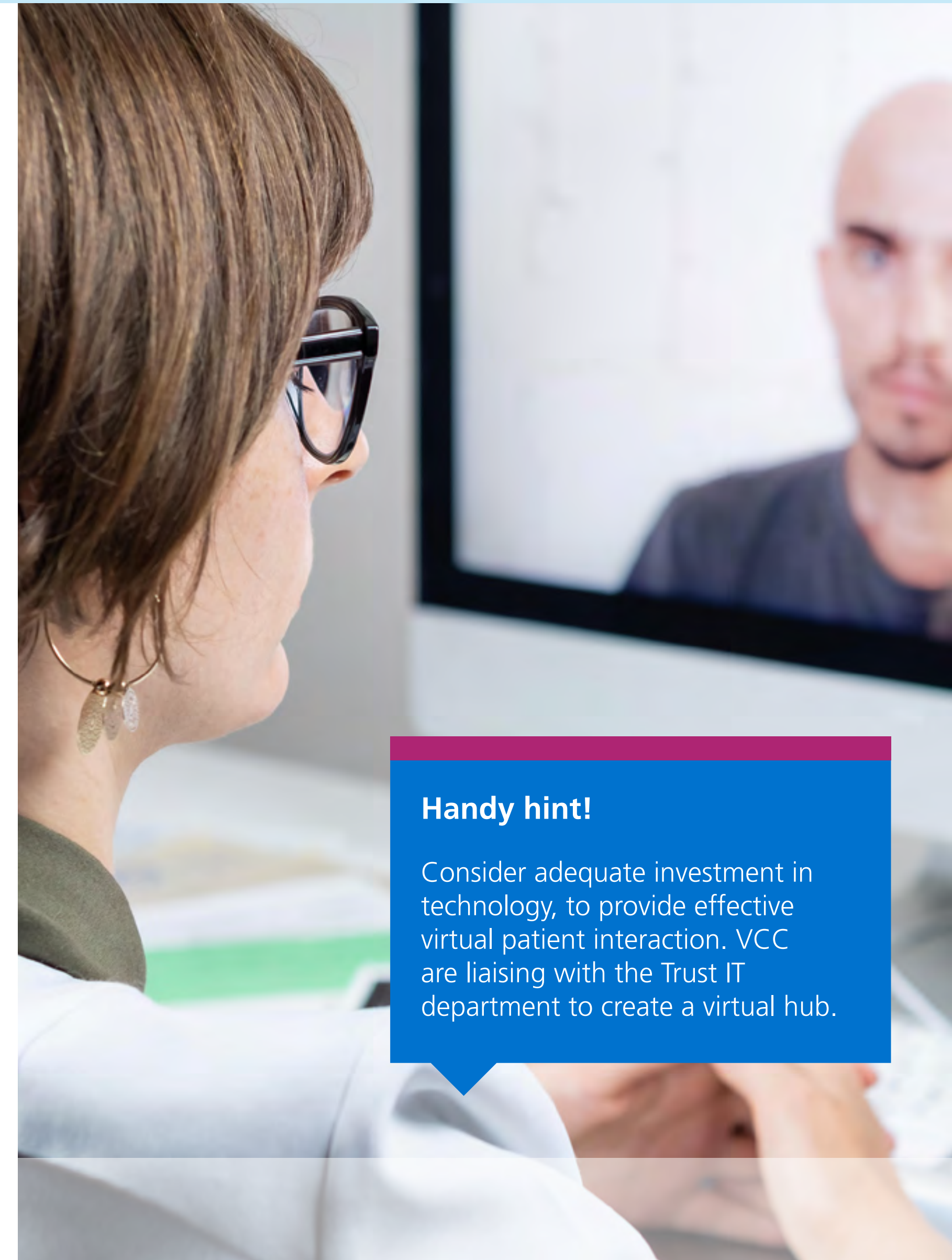
Extension of funding (providing 19 months in total)



Review clinic also implemented, in a virtual platform. Dietetic and Physiotherapy added into the clinic model.



An exploration of sustainable funding is underway, including investment in equipment.



Handy hint!

Consider adequate investment in technology, to provide effective virtual patient interaction. VCC are liaising with the Trust IT department to create a virtual hub.



Data Collection

Approximately 150 new neuro-oncology patients attend VCC each year.

Please click on this link, to see the performance data under individual staff groups involved in the Neuro-oncology clinics (initial and review appointments), and patient feedback data.



Outcome Measures

Significant work and review of national benchmarking has been conducted to ascertain the best standardised outcomes. With no consensus on the best outcome tool for this neuro-oncology patient population, the MDT team have devised their own tool, which is being piloted.



Financial Outcomes

In quarter 3 of the project, the joint neuro-oncology clinic was evaluated, comparing time provided for care pre- and post- the transformational bid:

Health-professional time in a routine patient pathway is reduced by 27%

Patient time spent attending the joint clinic (rather than a different single professional appointments) is reduced by 66%



Sustainability of Funding

We asked the MDT whether they have any hints for implementing and funding projects in the longer term.

- **Plan well in advance:** The project has taken a long time to implement and reach its current potential. Changes were implemented as the funding changed, and the needs of the patient group also changed.
- **Use appropriate outcome measurement tools:** “The MDT are to trial a locally created outcome measure for neuro-oncology patients. Finding a suitable tool for this patient group has proved challenging to meet their specific needs.”
- **Communicate with stakeholders to support sustainable funding:** “This neuro-oncology clinic provides a gold standard model of care within neuro-oncology patients. The stakeholders are reviewing how, with investment, this service can be replicated as part of our core service delivery, across other tumour sites at VCC.”
- **Adapt to changing patient demographics:** The development of a virtual model of care was implemented quickly, and there is continued review of services following the onset of the pandemic: “With COVID-19 it is anticipated the number of patients receiving a late diagnosis, or presenting with deconditioning due to shielding, will rise. This will lead to increased demand on AHP services.”

Summary of the Transformational MDT Review Clinic

This meets several key aims of the Outpatients Strategy 2020-23:

- Reduces waiting times and delays to services
- Reduces face to face outpatient appointments
- Reduces DNAs across specialities
- Symptoms managed in proactive way in a cohesive pathway

Additional benefits of joint review clinic:

- Reduces travel for patients, with virtual working
- Avoids multiple hospital appointments with different AHPs
- Increases patient and carer experience and quality of life: Reduces fragmentation in care. Limits unmet patient needs, crisis point management, and inpatient hospital admissions
- Achieves VCC organisational benefits – putting the cancer centre at the forefront of innovative and gold standard care
- Financial saving - reduced number and time spent within outpatient appointments, across the different health professions within the MDT.



Establishing the case for the project: An example in Lung cancer services in Barts Health NHS Trust

What benefit does prehabilitation have in this Lung cancer patient group?

Use existing research, policies, guidance, and pathways, to establish a case for funding.

For example, “There is a growing body of evidence that prehab can improve patient fitness for surgery, reducing post-operative complications, and length of stay.”¹

Use existing models of care:

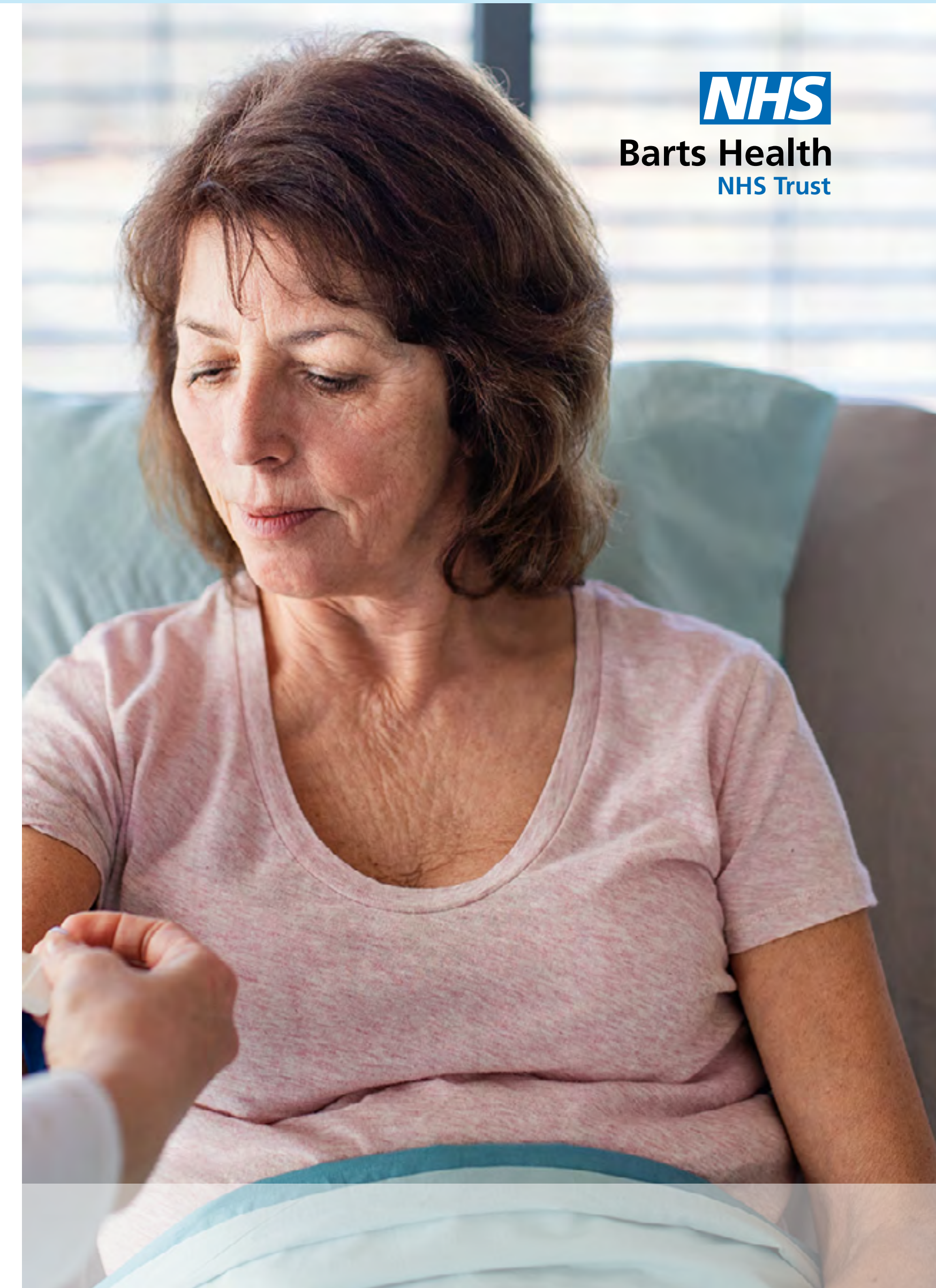
When an intervention promoting physical and mental health is already established, use this data in the case for funding. For example, lung cancer pathways are often linked into COPD pathways, keeping costs lower.

Use national data already gathered

For e.g., the National Lung Cancer Audit (NLCA).

Why look at this cancer site?

Stress the importance of the case for funding with research, local policy and strategies. “The UK has low lung cancer survival when compared with European comparators. Estimated five year survival (2010-2014) among the lowest in Europe”¹



Why is prehabilitation before surgery required?

Look at all available data, or build a case if there is no existing data. There was no current evidence about improving surgical resection rates in patients with borderline fitness. The case for the Barts Health NHS Trust programme was supported by Dr Will Ricketts, as surgery is the gold standard treatment for early stage lung cancer. However >40% of patients with early stage disease and a WHO performance status of 0-2 (i.e. able to carry out ambulatory tasks) were still not receiving surgery². Poor cardiorespiratory fitness due to COPD is the leading cause for this. Therefore, could interventions addressing fitness with COPD increase resection rates?

Outcomes for Barts Health NHS Trust Lung cancer project:

This prehabilitation programme is the first to address the fitness of patients, who may otherwise not be able to receive lifesaving surgery. As reported in the National Lung Cancer Audit, rates of surgical resection in Barts Health NHS Trust have improved from a negative outlier (12.8%) at implementation of the programme, to achieving the highest resection rate in the country (33.3%)¹. No increase in mortality or length of stay in the acute setting was observed. There was no significant delay in the 62-day treatment pathway. Physical and quality measures also showed statistical improvement in: 6-minute walk test distance; 5 times sit-to-stand time; Forced expiratory volume in 1 second (FEV1); EQ-5D-5L

Funding:

Dr Will Ricketts recommends:

- Making links with your local services to negotiate fast-tracked referrals. This can keep costs low, using existing programmes (e.g. smoking cessation and pulmonary rehabilitation), and existing staffing structures. This programme was led by the Oncology Outpatient Physiotherapy team, and across the pathway also included intensive inpatient prehabilitation (a Cardio-respiratory Physiotherapy service) and standard Pulmonary Rehabilitation (under the Community Respiratory Team).
- Investment in administration staffing required to manage referrals.
- Investment in digital app for patients, e.g. <https://setup.livingwith.health/new-clinic/product/lwlc>

Support to build your own business case




MSD's work supporting Cancer Clinical Nurse Specialists

Clinical Nurse Specialists (CNS) are at the frontline of cancer treatment

For the stages and guidance on developing a personalised care project, please see the attached document, by Merck Sharp & Dohme

The document outlines the processes for establishing a case in cancer prehabilitation.

[Download](#)



NHS Wessex Cancer Alliance

Workforce and Education

Fran Williams (NHS England & NHS Improvement) shared a recent piece of work completed under Wessex Cancer Alliance, to develop a case for Cancer Support Workers.

The red and highlighted areas are left blank for you to fill in your individual organisational data.

[Download](#)

Funding & clinic development pathway

The following section outlines the learning from a project, provided across the Gloucestershire region (in England), for some of the transferable skills that could be applied to your own project, across the UK. This used learning from existing rehabilitation programmes (Pulmonary, Cardiac, and Cancer), to develop a strategic approach to cancer rehabilitation.



Sara Mathewson (Macmillan Partnership Manager) outlines the project development stages within the Macmillan Next Steps Cancer Rehabilitation programme. These can be summarised under the following areas:

Outline the proposed strategic direction of this project within cancer services / wider health and social care structure

Look at accessible funding routes (using existing, or new staff structures)

Outline a project plan by reviewing data within similar existing programmes (timeframes, budget, aim, outcomes)

Engage with key stakeholders

Evaluate the programme at key stages

Strategic direction of the Macmillan Next Steps Cancer Rehabilitation project

The project commenced in 2015, following the development and recruitment into the leadership roles for the project. The Macmillan Partnership Manager, and the AHP Consultant Lead were brought into the project at the initiation stage, to develop the project plan, and lead on recruitment to the Project Development Team, over the following years. A report on summary of this work is available [here](#)¹

Funding for the development of the project

Funding was required for staffing and programme delivery, with Macmillan Cancer Support providing this initial funding. The timeframe for project development and the implementation was provided on a fixed term basis, over 2 years.

- This included establishing a new Project Development Team, including:
 - » AHP Consultant Lead
 - » Project Manager
 - » Project Coordinator
 - » Dietitian
 - » Physiotherapist
 - » Therapy Assistant Practitioner
 - » Senior Health Trainer (X2 posts)
- The team supported the assessment of existing data on (cancer) rehabilitation programmes, engaging with key stakeholders, developing the programme content across the acute and community teams, producing reports, and seeking a sustainable source of funding for the continuation of the programme.





Role of the Project Development Team: Reviewing existing data

What pre-existing data was linked into the stratified pathways for the programme?

Cancer rehabilitation programmes had already been established in North Cotswolds and Gloucester City. Data gathered through the analysis of these existing programmes supported the project development process, including a service-wide review to address:

- A focus initially on 3 Cancer types: within the 3 largest cancer groups being diagnosed with cancer across the region (colorectal, prostate, and breast).
- The issues connecting and supporting men, rather than women.
- The IMD data, that men living in Gloucester City have a 10-years lower life expectancy, than men living in the most affluent area, the North Cotswolds.
- Why men in Gloucester City, were much less likely to engage in the invitation to a 1-2-1 appointment, versus men in the North Cotswolds.
- Less engagement in rehabilitation programmes from some cultural groups, and those with another first language than English.

Developing the new programme took account of the above factors, trying to access groups with prior limited engagement.

Role of the Project Development Team: Developing programme content and delivery

What pre-existing data was linked into the stratified pathways for the programme?

- The Project Development Team ensured several key factors were addressed in the delivery of new Macmillan Next Steps Cancer Rehabilitation programme:
- Engagement with the different patient groups (including those who failed to engage in earlier rehabilitation programmes):
 - » Advertising and promoting the programme in the Acute Trusts
 - » Engaging with health professionals working across primary and secondary care, who were providing referrals
 - » Using Gloucester FM radio, to connect with the BAME audience
 - » Developing a 'Friendship café', run by local religious leader (Imam), to promote the programme, and for health professionals to provide advice
 - » From the outset, to ensure referrals were received efficiently across the tumour sites.
 - » To ensure data was collected from primary and secondary care, recording outcome measures, against anticipated performance targets.



Stakeholder engagement

Engage with key stakeholders early, for example, within the Macmillan Next Steps Cancer Rehabilitation programme across Gloucestershire, this included:

- Patient groups
- Gloucestershire CCG
- Acute sector engagement: Leads in Cancer types - CNS, Consultants, Surgeons, and Director of Nursing
- Community / secondary care: Engaged with a GP who provided a list of all the patients registered at the practice with a Cancer diagnosis. The team were then able to contact each patient and offer an invite to the programme.
- Psychologist, Occupational Therapy, Dietitian, Physiotherapy (wider Allied Health Professional networks)
- Charity organisations: Macmillan, CRUK
- PDSA cycle - lung, gynaecology, colorectal, prostate (latter funded a Fixed Term Nursing post within the team)

Using data gathered for a case for sustainable funding

It is advisable to link outcome measures into performance and service evaluation reports:

In this project, the team outlined the evaluation of the data collected in clinical practice, including outcome measures, and Key Performance Indicators. This was used to build a case for sustainable funding. The outcome measures were mainly those already being collected in clinical practice, allowing a review of data across a period of time, when different programmes were being provided.

Using this evaluation of the data, following the 2 years fixed term period provided initially, Macmillan Cancer Support continued the funding of the programme delivery, alongside the Trusts / CCG (the acute and community teams).

From January 2021, funding supported the development of a Cancer Personalised Care Prehabilitation programme. Additionally, teams across the larger geographical area of SWAG (Somerset, Wiltshire, Avon & Gloucestershire), are using a cancer alliance wide approach, to support the late effects programme, in rehabilitation.

Factors to consider in developing a project

- Look across the whole process to establish all costs to enable the project to run effectively:
 - » Office or clinical equipment required in addition to existing resources
 - » Stakeholder development and engagement (administration time to develop literature, and plan / attend meetings)
 - » Investment in IT systems for joined up services and efficient referrals

Examples within the Gloucestershire project

- The team had to find additional funding for scanner (to go paperless for referrals etc)
- Computer software was required across the acute and community teams. Because they used different systems, funding was required for both systems - this was an increase in expenditure, which was not accounted for at the outset.
- Funding was not agreed initially for Administrative support, therefore added into the role for the Project Coordinator.

- Before recruiting for the project development team or clinical teams, ensure the project can run efficiently: Are there going to be any issues for staff once they commence?

- The Project Lead and team were not allocated time within the fixed term project to set up the area of work – time was therefore used to locate adequate office space, with an impact on other deadlines.

Factors to consider in developing a project

Examples within the Gloucestershire project

- Implementation of the service - timeframes, staffing recruitment.



- Investment into development of an Integrated Care System

- Evaluation of the service – Depending on the scale of the project, the final evaluation can be >10% of the total project costs.



- Not enough money was provided in the initial budgeting, to be able to analyse, evaluate and publish the findings.

- Address misconceptions which can act as a barrier to implementing or sustaining the service.



- For example, patients do not survive cancer, or that those who are palliative, do not require rehabilitation.

- Promotion of the project: Including time for developing and printing posters, engaging with communications teams across different care systems.



- Be careful with language used, as the programme was outlined as a “gold standard” of care in the project summary. Ongoing funding looked at a smaller programme with the belief that gold level was no longer required, as this had been ‘achieved’.

Factors to consider in developing a project

- Ensure clear allocation of roles within the Project Team, and Stakeholder engagement processes:
 - » Who is responsible for different aspects of the care pathway?
 - » Which clinical professionals are required to assess patients' at the different stages of their care?
 - » Do not underestimate the need for Clinical / Cancer Support Workers and Administration staff to help the project run smoothly.
Download [a guide to funding a Cancer Support Worker role](#).
- Establish who the key contacts and stakeholders are, early in the process:
 - » Have they been fully informed of the intended outcomes for the service being developed, and time frames for the project implementation? This engagement can take a lot of time at the outset of the project, especially if contacts are not aware of the service being developed.
 - » Ensure Leads in cancer types are engaged early – this engagement is required to understand how the referral processes will work.
 - » These are just a few examples of the factors to consider in developing your own project. Look across other existing case studies, and at the [Cost Consequences Calculator](#) in this guide (to establish the costs / benefits for establishing your own project).





Implementing projects across cancer services

This section briefly explains, how the implementation of cancer projects can be supported in different ways, across the system. We have outlined some of the work underway across Scotland, within cancer prehabilitation, looking across national policy, and local agenda, within the wider context of health and social care.

Development of policy: Published in December 2020, Recovery and Redesign: An Action Plan for Cancer Services, sets out the plan for testing and evaluating cancer prehabilitation in Scotland. The focus of the work is guided by a scoping exercise carried out in 2019/2020; with the final report available [here](#). All services will continue to develop over time, with the actions outlined from the National Cancer Plan, establishing a strong foundation for prehabilitation in Scotland. The increasing momentum in this field, supports the development of services for people affected by cancer, from the earliest possible point in their cancer journey.

To test a universal prehabilitation service, the Scottish Government is piloting several prehabilitation projects, in partnership with Maggie's. This pilot is available in each of the 8 Scottish Maggie's centres, from early 2022, through to 2023.

Implementing prehabilitation in local agendas:

Prehabilitation is an emerging field, with a number of locally developed prehabilitation offers across Scotland, revealed by the above scoping exercise of services. One such example, is the **HARP project** in Ayrshire & Arran.

Highlighting key stakeholders involved

in cancer prehabilitation: To support local and national agendas, a Cancer Prehabilitation Implementation Steering Group (CPISG), chaired by Professor Annie Anderson, was implemented in Scotland.

The CPISG is supported by 3 subgroups, which look to:

- Develop a digital offer that will support the delivery of tri-modal prehabilitation, improve access to education and training, and support measurement to improve understanding of what works and in what context (Digital subgroup)
- Look to the West of Scotland's Psychological Therapies and Support Framework for potential learning what can be adopted across the country, supporting access to psychological care and support (Psychological subgroup)
- Develop and implement a nutrition framework for prehabilitation (Nutrition subgroup)

Viewing prehabilitation in the wider strategic context:

- The prehabilitation ambitions set out within the National Cancer Plan are aligned with the wider **Framework for supporting people through Recovery and Rehabilitation during and after the COVID-19 Pandemic** (Scottish Government, 2020), and there is also a focus on cancer and prehabilitation within the over-arching **NHS Recovery Plan** (Scottish Government, 2021). This demonstrates the commitment of the Scottish Government to support cancer service provision, with high quality, holistic, person-centred care.
- Research into cancer care is also an influential part of the cancer continuum. In Scotland, this includes for example, the James Lind Alliance and NIHR. Funding for research is supported by alliance between the different agencies, including the Chief Scientist Office (CSO) in Scotland (<https://www.cso.scot.nhs.uk/>)





Using key stakeholders – Nationwide support

We will now look in more detail about the engagement with stakeholders, particularly those making decisions about the future of cancer care in a geographical region, and across a nation. Examples of stakeholder engagement across several nations, are outlined briefly within this section.

Local level engagement: Key stakeholders can include colleagues working across primary and secondary care, or those currently or previously engaged in projects, which can potentially support your work. An example of using contacts, to successfully develop and establish a service, is provided within the Gloucestershire Macmillan Next Steps Cancer Rehabilitation programme.

A great example of stakeholder engagement is also showcased within a holistic programme, running across several cancer types, in South Eastern Health and Social Care Trust (Northern Ireland). This programme is occurring within the wider context of policy change and strategic framework implementation, across cancer services in Northern Ireland.

Dr Cherith Semple (Reader in Clinical Cancer Nursing, Ulster University/Ulster Hospital), outlines details of this programme:

Development of a Cancer Prehabilitation programme in South Eastern Health and Social Care Trust, Northern Ireland

What are the main factors supporting the development of this prehabilitation programme?

Stakeholder engagement: Our partnership pilot project, has an integrated delivery between South Eastern Health & Social Care Trust, local councils (Lisburn City & Castlereagh Council, Newry Mourne & Down Council, Ards and North Down Council, Belfast City Council), Macmillan Cancer Support, and Ulster University.

Main selling points for the programme:

This is a multimodal programme, incorporating a holistic person-centred, stepped model pathway of care across three tumour groups, with: Exercise and physical activity, nutrition advice, emotional support, smoking cessation, and support for alcohol reduction.

Adaptions to the programme: This programme was developed and delivered during COVID-19. Therefore, it was delivered virtually or in leisure centres, when local government COVID-19 guidelines supported this. This provided patients with access to services at home, or close to where they live, across the South Eastern Health & Social Care Trust area.



Data collection: Patient feedback on the programme

Benefits for the patients:

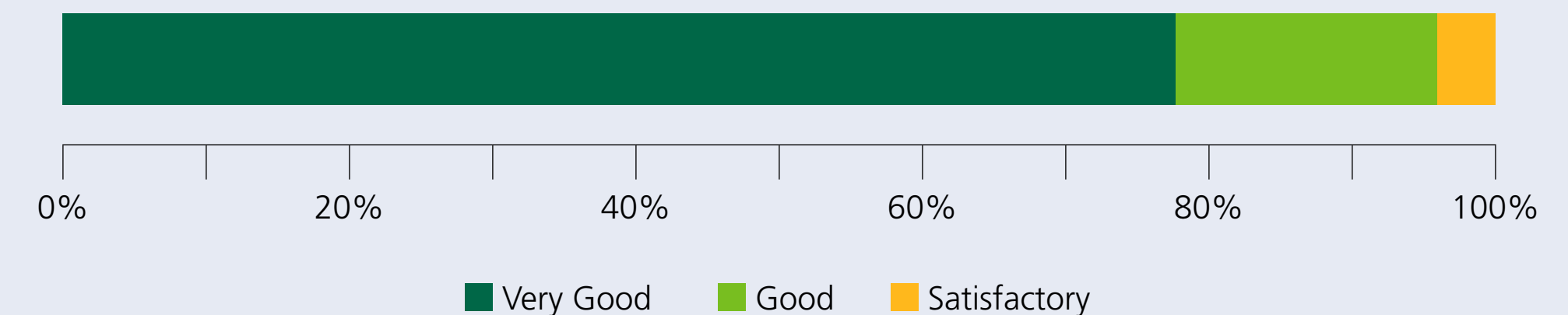
Patients have an opportunity to take control of key aspects of their life, at a time of additional stress and uncertainty, ensued from a cancer diagnosis. This programme:

- Optimises psychological and physiological wellbeing (physical activity, nutritional status, emotional wellbeing, and treatment-related functional impact).
- Increases patients cardiovascular and skeletal muscle fitness prior to treatment.
- Supports lifestyle behaviour changes, prior to treatment, throughout treatment, and beyond.
- Provides holistic support, by signposting to support services such as Stop Smoking and Substance Misuse Support.

Patients reported on the benefits of involving friends and family in the programme, for a joint approach to learning about the benefits of a healthy lifestyle. Access to local leisure facilities for free for an agreed period of time, before and after treatment, also provides a real initiative to increasing physical activity levels.



Patient reported experience measures (PREMS) showcased the feedback from individuals, after 3 months of engaging with the programme. This data shows feedback from 55 people:



Outcome Measures – Data and feedback

What are the main benefits of this programme for staff?

Staff are involved in cutting edge, evidence-based care. Macmillan Move More Coordinators additionally received development and training opportunities, for the upskilling of staff to deliver the programme.

Provisional data is currently being collected, showing the data change from implementation, through the regular review of the programme.

Using the data to support sustainability of funding:

The above data has supported on-going funding, for further rollout of the programme during 2022. This is provided by a successful Cancer Charities bid, with funding from Macmillan Cancer Support.



“

“When the person with cancer is the most important person, then collaborative working is easy. Congratulations on such an excellent integrated project, made possible through an inspirational team of people bringing together cancer services, health improvement, councils and Macmillan Move Move. Let’s do more of this!”

Lorna Nevin, Macmillan Partnership Manager (NI)



Stakeholder engagement nationwide

Wales has showcased some great examples of using **wider agencies and organisations**, supporting sustainable project outcomes and funding. For example, one team linked in with the Centre of Perioperative Care for Surgical Pathways, supporting a colorectal and upper gastrointestinal cancer surgery programme, in Wrexham Maelor Hospital

With engagement at the **political level**, the Integrated Health Boards provided the go-ahead for an across-service cancer model throughout Wales, delivering this across the 7 local health boards, and 3 NHS Trusts in NHS Wales. The Health Boards have a key role in improving physical and mental health outcomes, promoting wellbeing, and reducing health inequalities.

Role of system-wide planning: Dr Rachael Barlow, Clinical Lead for the Surgical Clinical Board (Cardiff and Vale University Health Board), is currently leading on an evaluation of cancer services across Wales, including a summary of the data gathered during the first 12 months of different projects. The aim of this is to provide seamless care, providing the different pathways to support care from pre-diagnosis through to post-treatment rehabilitation (curative and palliative).

Stakeholder engagement nationwide

Financial impact: Utilising national models of care (i.e. those supported within a systems wide approach to funding), can potentially increase cost when services and / or equipment need to be implemented. Therefore, in a tight budget we may need to be selective of the processes being employed. Using existing services, such as local leisure centres, existing public health initiatives, and existing clinical equipment, can potentially keep costs lower. An example of utilising existing services (e.g., clinic space, and anthropometric equipment in the clinical areas), is shown in the prehabilitation pre-diagnosis clinic running in Cardiff and Vale University Health Board.

Investment in training and staff development: The system wide approach, across the different nations, has supported the development of specialist clinical training, with an emphasis on developing health professional and support worker roles, to achieve specialist personalised care for the cancer patient. Investment in the workforce is essential for job satisfaction, and to develop a health and care system to support the changing demographics of population. Across the nations, there has been investment in supporting staff with advanced practice training, i.e. training for those who are already working in a professional field, hoping to, or already specialising in, a particular area of practice.

Documents are available to support this staff development in your organisation. For example, in Wales, this includes the Advanced Practice:

The Portfolio.



The costs and impact introducing prehabilitation and rehabilitation services

It is important to consider the costs and consequences of implementing prehabilitation and rehabilitation services. Decision makers and clinical leaders within the health and social care system need to understand the economic impact of any new initiatives.

- Below is a link to a cost-consequences calculator, to enable you to estimate the costs and the impacts of implementing a Personalised Care project in your organisation.
- The calculator is useful in a number of ways. It can:
 - » Act as a checklist for understanding what measures to consider and the data to collect
 - » Be used to help develop a business case to demonstrate potential or expected costs and impacts
 - » Be used to consider benefits realisation when a project has been running for a period of time and data have been collected on costs and impacts
- The calculator includes worked examples to demonstrate changes in the costs and the patient and other clinical outcomes, based on case study projects.
- You are able to use your own data in the calculator to carry out your own estimates and develop economic scenarios.

The cost consequences calculator has been produced by York Health Economics Consortium.



Promoting your project



The key to any project is ensuring you have engaged with the right people, and used different resources to advertise and promote the project.



Prehabilitation in particular can be used in different contexts, and explained in different terms. It is very important you have a clear explanation of the project being offered.



Use only relevant images, for example, a photograph of the actual exercise class, the gym, etc. Use images that support the description, and show what is actually provided.

What is the project called? Use clear language, outlining what the intervention will provide, for example:

- Preparation for radiation therapy
- Support to understand your surgery and hormone treatment
- Sessions to support your physical health and mental health
- Support for your recovery after surgery
- Getting people physically and mentally as fit as possible for treatment

A Patient engagement project, funded under RCoA, NIHR, and Macmillan

- Patient engagement work that supported the development of the national prehabilitation in cancer guidance asked patients what a prehabilitation programme should be called: “What we as patients need before, during and after treatment is a series of plans, which we are involved in, so why not call this initiative ‘Pre-treatment plan’ or something else, which is more transparent”
- “Prehabilitation is important but its not prehab its preparation...need to use the right language to help people understand.”
- “Getting fit for treatment”

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Acknowledgements

A special thank you goes to all of the contributors to the Guide, especially those living with, or recovering from, cancer (who cannot be named for confidentiality reasons).

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Acknowledgements

A special thank you goes to all of the contributors to the Guide, especially those living with, or recovering from, their cancer (who cannot be named for confidentiality reasons).

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