# Macmillan Prehabilitation Project

# Calderdale & Huddersfield NHS Foundation Trust

# West Yorkshire & Harrogate Cancer Alliance

## Report compiled by: Nicky Hill

Report to cover period from 1st April 2019 to 31st March 2020

# Contents List



**Abbreviations**

| | |
|---|---|
| CHFT | Calderdale & Huddersfield Foundation Trust |
| HNA | Holistic Needs Assessment |
| PAM | Patient Activation Measure |
| NHS | National Health Service |
| NHSE | National Health Service England |
| CNS | Clinical Nurse Specialist |
| WHO | World Health Organisation |
| BMI | Body Mass Index |
| MDT | Multi-disciplinary team |
| COPD | Chronic Obstructive Pulmonary Disease |
| ISWT | Incremental Shuttle Walk Test |
| IPAQ | International Physical Activity Questionnaire |
| CMO | Chief Medical Officer |
| GI | Gastro Intestinal |

# Section 1 Executive summary

The Trust identified a need for, and the benefits of, Prehabilitation and how this could potentially improve outcomes for cancer patients. It was agreed in collaboration with Macmillan to explore the feasibility of offering Prehabilitation within our existing acute and community services as a project for 2 years.

Nationally, one out of two people in England will develop cancer at some time in their lives (Cancer Research UK, 2015). With the development of better treatment for cancer patients, in conjunction with an increased chance of survival for people with cancer, demand on cancer services will continue to grow. Supporting people to live well with and beyond cancer is central to ensuring their experiences and quality of life is maintained. The provision of some services cannot always be increased to meet the demand, therefore new ways of working and the support offered to people may need to adapt. Reducing unnecessary demand and strain can be achieved in providing patients with the access to the right information, at the right time and at the right level, to support them have choice and control of decisions made, and to ensure their treatment and care is individual and personalised throughout.
Supporting people with cancer from the moment they are diagnosed can offer the opportunity for health care professionals to explore how best to support and identify what they require at the very beginning, to be able to have control in supporting themselves throughout the rest of their cancer experience, equipping them with the knowledge, skill and confidence to be able to have an active role in their cancer care and shared decision making.

The Prehabilitation project has identified ways, in which people with cancer can be supported, from the point of diagnosis, by adapting the support offer, widening resource available, having meaningful conversations and giving patients the confidence to take responsibility to improve their cancer experience.
The development of the health and wellbeing strategy has been critical in supporting the offer of Prehabilitation to all newly diagnosed cancer patients.

The project also has;

- Assessment and screening to support patients with more complex needs, participate in targeted and specialist interventions and is being tested with Lung cancer patients.
- Supported the NHS Long Term Plan Personalised Care agenda by developing personalised Prehabilitation care and support plans, using the Patient Activation Measure and ‘What matters to Me…’ questions.
- Engaged stakeholders in providing support and interventions to patients requiring Prehabilitation, including leisure service providers, social prescriber link workers, pulmonary rehabilitation and smoking cessation services.

The Prehabilitation project has demonstrated the patients who participate in Prehabilitation interventions describe an improvement to quality of life and experience by being more equipped with information and support to help them before and during their treatment. It’s also led to improvements to their physical and emotional well-being.
The first year of the project has demonstrated that development of information services with a whole population approaches to Prehabilitation in offering information, education and support to prepare people for their cancer journey can be achieve within CHFT.
The next year of the project aims to explore a more tailored approach to support individual patients in more detail. Identifying areas where more support is required in relation to tumour site, socio-economic and ethnic demographics and working with partner organisation and stakeholders determine who is best placed to deliver this and how.

## Section 2 Introduction

The role of the Project Manager has involved piloting and testing ideas and models with identified patients and undertaking ultimate responsibility and accountability for the project. The two-year funded Macmillan Prehabilitation Project commenced in April 2019. The project is led by a band 7 Project Manager with over 20 years healthcare experience as an Occupational Therapist, seconded from CHFT.

The aim of this annual report is to detail the progress of the project to date with further evaluation pertaining to emerging evidence which surrounds the benefits of Prehabilitation for cancer patients. An attempt will then be made to highlight how developments in practice have guided the direction of the project and subsequent advancements in relation to service development.

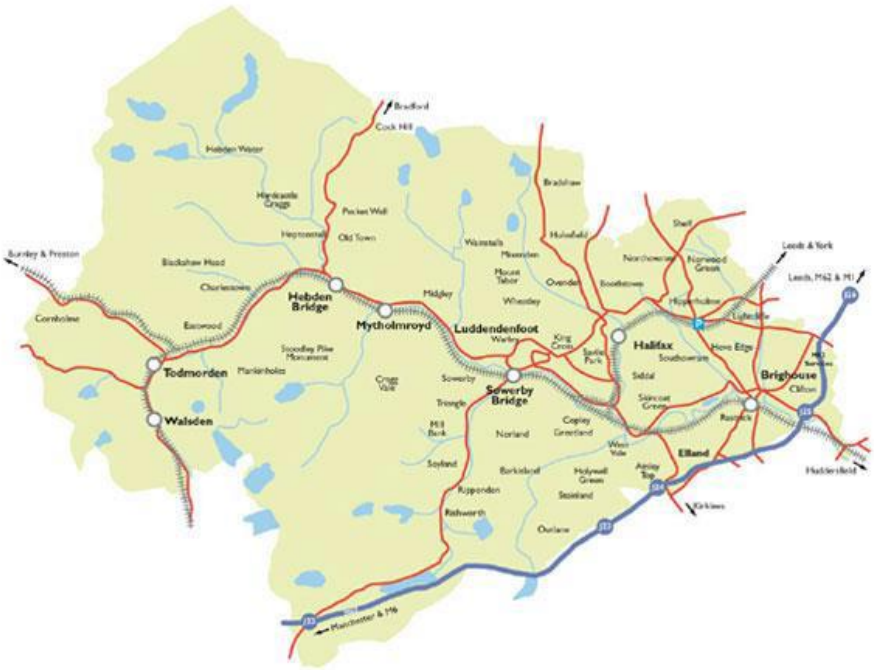
A key focus within this report will relate to patient experience, involvement and feedback in order to validate and drive forward the concept of prehabilitation. Furthermore, it will attempt to justify the benefits Prehabilitation possesses towards improved outcomes for people affected by cancer; particularly by promoting health and wellbeing and supporting cancer survivorship.

Finally, the report will illustrate the broad role the Project Manager has undertaken in supporting cancer patients within CHFT and the support extended to the wider Trust, Macmillan, West Yorkshire and Harrogate Cancer Alliance and National Agendas. The use of both quantitative and qualitative data, in addition to service user feedback will be included to further demonstrate how different elements of prehabilitation are being embedded across cancer services.

## Section 3 Relevant demographic profile of the population served

**Calderdale** comprises of the main towns of Brighouse, Elland, Halifax, Hebden Bridge, Sowerby Bridge and Todmorden. Calderdale is one of the smallest districts in England in terms of population, but one of the largest in terms of area as it covers 140 miles.

The district is served by NHS Calderdale Clinical Commissioning Group. In June 2018 the Office for National Statistics (ONS) published its 2017 mid-year population estimates, which indicated that there are 209,500 people living in Calderdale which is an increase of approximately 5,600 people since the 2011 Census.





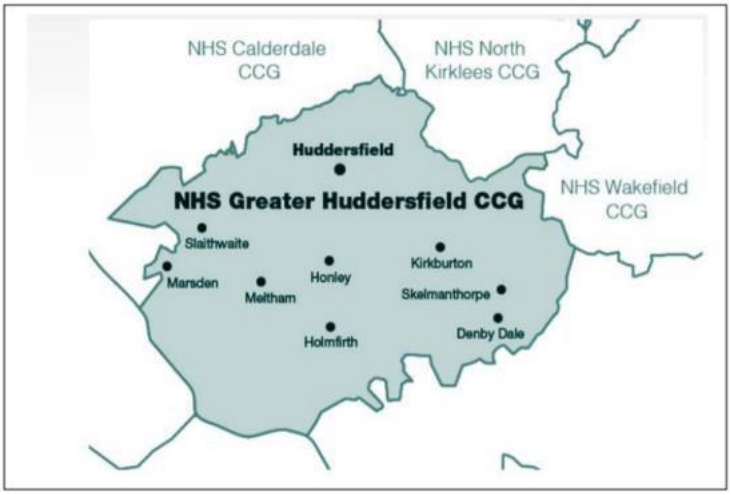

The largest ethnic group in Calderdale is White British (89.7%), as recorded in June 2018. The second largest ethnic group is Asian /Asian British (8.3%) of which the majority (6.8%) are Pakistani.
**Source** – calderdale.gov.uk

For both males and females in Calderdale, cancer is the biggest contributor to life expectancy, followed by respiratory conditions and circulatory conditions. Over 1,100 cases of cancer are diagnosed each year in Calderdale residents and around 550 residents die each year from cancer. Over half of all cancers could be prevented by changes to lifestyle (e.g. diet, alcohol intake, obesity). Smoking is the single largest preventable risk factor for cancer in Calderdale.
**Source** – calderdale.gov.uk

**Kirklees:** Measured in population terms, Kirklees is one of the larger local authority districts in England and Wales, ranking eleventh out of 348 districts and covering 157 square miles. The overall population of Kirklees rose to 437,000 in 2017 (Source Kirklees.go.uk) with a population

of over 245,000. The district contains both high and low areas of deprivation with regions of highest deprivation found in some of the more densely populated areas (Huddersfield, Dewsbury and Batley).


The metropolitan district of Kirklees is served by two Clinical Commissioning Groups – NHS North Kirklees CCG and NHS Greater Huddersfield CCG. The patients in Kirklees seen at CHFT for prehabilitation will be those within the Greater Huddersfield CCG, which has a population of 247,000 people, approximately 58% of the Kirklees Council area. North Kirklees CCG area falls within services at Mid Yorkshire NHS Trust.




Kirklees is an ethnically diverse population, as illustrated in the table below.

| Ethnicity | Count | % |
|---|---|---|
| White British | 323,890 | 76.7% |
| White other | 10,380 | 2.5% |
| Pakistani | 41,802 | 9.9% |
| Indian | 20,797 | 4.9% |
| Black | 7,905 | 1.9% |
| Mixed | 9,790 | 2.3% |
| Other | 7,894 | 1.9% |

According to the 2011 census, 91.7% of the Kirklees population have English as their first language. Other languages in this area are as follows:

| Main language | Count | % |
|---|---|---|
| English | 370572 | 91.4% |
| Panjabi | 9706 | 2.4% |
| Urdu | 6685 | 1.6% |
| Gujarati | 5897 | 1.5% |
| Polish | 2912 | 0.7% |
| Other | 9,580 | 2.4% |

Source – Kirklees.gov.uk

The prehabilitation project has developed information for patients in English initially; however, support can be accessed in other languages by accessing 'The Big Word' interpreters via the Trust.

Cancer remains the most common cause of death in under 75s in the Greater Huddersfield area and more people die from lung cancer than from any other type of cancer. Rates of new breast, prostate and bowel cancer diagnoses are higher in our area than in the Kirklees average.

## Section 4 Service aim, objectives and expected outcomes

The primary function of the Prehabilitation Project is to explore the feasibility of developing and delivering a model of Prehabilitation. It aims to utilise or adapt existing services delivered in the Acute Trust and the Local Community to support the psychological wellbeing, nutritional and physical activity needs of newly diagnosed cancer patients. The ultimate aim involves optimising the patient's health and wellbeing before, during and after primary cancer treatment. It is expected that following a period of Prehabilitation patients will have increased fitness, both physically and mentally, with significantly improved outcomes.

The expected outcomes will be:

- A larger proportion of patients accessing cancer services
- Improved patient and carer experience
- Increased numbers of patients receiving first line treatment
- Increased number of patients receiving and tolerating second line treatment
- More access to health and wellbeing information to promote positive behavior change in preparation for cancer treatment.

Objectives –

1. To develop and deliver an offer of universal Prehabilitation to all newly diagnosed cancer patients.
2. To explore current service provision in the Acute Trust and Community, potentially engaging service providers in the delivery of prehabilitation where possible.
3. To develop and test outcome measures to assess and stratify patients in the delivery of individual Prehabilitation support plans.
4. To trial specific physical activity interventions with a cohort of newly diagnosed cancer patients.
5. To engage Community Partners in the provision of targeted and specialist Prehabilitation across Calderdale and Huddersfield.
6. To support and engage those patients who would historically have not had access to or sought support in health and wellbeing during cancer treatment.
7. To support the delivery of the Personalised Care agenda in line with guidance and recommendations from the NHS Long Term Plan.
8. To link closely with support & services offered by the Macmillan Information Service within CHFT in the delivery of Prehabilitation.
9. To offer an individual, personalised prehabilitation care plan to those patients who require targeted and specialist interventions due to pre-existing conditions and are at higher risk of complications.

Identification of people with cancer requiring Prehabilitation should occur as early as possible from diagnosis. Silver and Baima (2013) describe cancer prehabilitaion as "a process on the cancer continuum of care that occurs between the time of cancer diagnosis and the beginning of acute treatment". Screening should use validated tools to identify the need for more detailed assessment in order to inform the prescription of targeted or specialist interventions. Screening should be aligned to the HNA and should include psychological risk factors, physical fitness, and nutrition, (Principles and guidance for prehabilitation within the management and support of people with cancer, 2019). Prehabilitation interventions can still be effective if begun as little as

two weeks prior to treatment, (Faithful S, Turner L, Poole K, et al 2019), reinforcing the benefits of identifying patients for prehabilitation as close to diagnosis as possible.

Outcome measures (objective 3)

The prehabilitation lead explored the options of which screening tools and outcome measures were recommended for use with patients for each of the components. Networking with colleagues locally, regionally and nationally also supported the decision making behind which assessments and screens were introduced. In the initial stages of the project the screening tools and assessments were trialed with three patients to determine suitability; their feedback was received regarding the timing of assessments and language used in patient information. Following this it was decided that the following outcome measures would be used–

Physical Activity

- International Physical Activity Questionnaire (IPAQ)
- Incremental Shuttle Walk Test
- Grip strength (Dynamometer)

Nutrition

- Patient Generated Subjective Global Assessment (PG-SGA)
- Height / weight / BMI

Psychological

- Patient Health Questionnaire (PHQ9)
- Generalised Anxiety Disorder Assessment (GAD7)

Outcome measures are completed with participants at agreed time intervals within assessment clinics:

1) Initial assessment (first face to face contact) approx. 60 mins,
2) Prior to commencement of cancer treatment (surgery, chemotherapy or radiotherapy) approx. 45 mins,
3) Post-cancer treatment (6 weeks post-surgery) approx. 45 mins,
4) Final assessment (12 weeks post-surgery) approx. 60 mins.

Guidance advises participants with oesophago-gastric cancers are re-assessed halfway through their neoadjuvant chemotherapy and when this has finished.

The outcome measures trialed and implemented with patients were and continue to be used as a method to assess and stratify patients to inform individual care and support plans. The outcome measures agreed for nutrition screening, physical activity levels and psychological support are being completed by the prehabilitation lead / project manager. It is intended that longer term, embedding an element of screening within the HNA and initial assessments by the MDT clinicians will then identify those that need further specialist assessment from the prehabilitation lead or registered health care professional in the specific area. This will support the sustainability and longevity of prehabilitation in every day cancer services.

NB. Some of the outcome measures require additional training and education to use, for example the ISWT.

The outcome measure tools and questionnaires were discussed and explained with two patient representatives to gain feedback and a personal insight in relation to length of time taken to complete, ease of administration, and understanding of questionnaires. Thirteen patients have participated in the project to date. In the initial phase three of the thirteen patients trialed the use of the outcome measures to determine their effectiveness in supporting the creation of individual prehabilitation plans and their use as outcome measures.

Referral pathways (objective 2)

Referral pathways from Acute to Community resources have been in place for some time however 'cancer and receiving cancer treatment' has often been an exclusion criterion. Developments have been made through this project to establish support for cancer patients accessing leisure services for physical activity interventions across Kirklees and Calderdale, with patients having support from a level 4 personal trainer. Cancer Prehabilitation has been included into the referral inclusion criteria for leisure service referrals. Weight management support existed prior to the project and is available through Weight Watchers and Slimming World, however when cancer clinical nurse specialists and support staff were canvassed very few were aware of these and didn't routinely refer or signpost their patients. Community Dietetic pathways are in place, however again not readily utilised by CNS's, and the dieticians have agreed to accept patients who require nutritional support as part of their prehabilitation and referral data and levels of intervention will be monitored. The CHFT Clinical Psychology team provides services to cancer patients. Following discussions around the role and value of Psychology in preparing patients for treatment and surgery and the introduction of the prehabilitation project, patients who require a level of psychological support greater than what is offered from a level 2 trained CNS, can now be referred into the specialist cancer psychology team. The impact of additional prehabilitation patients accessing the service will be monitored through their referral audit.

Universal Prehabilitation offer – First Steps (objective 1 & 8)

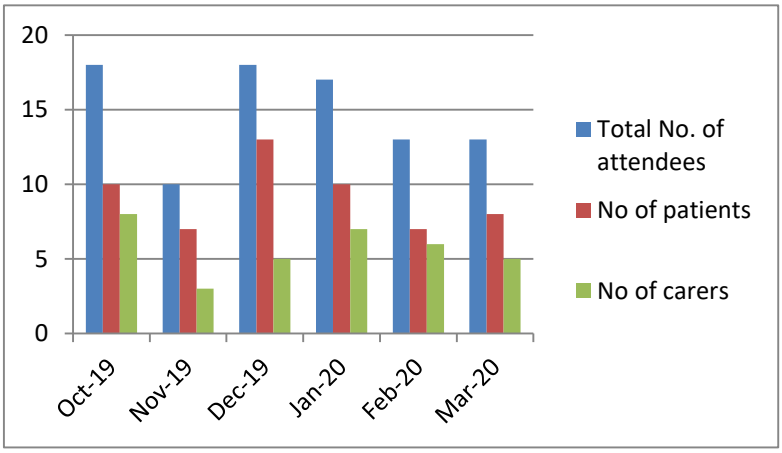
Universal Prehabilitation is applicable to anyone with cancer. Providing information and education to support people to stay well improve resilience and empower them to have control over the decisions made and the care they receive. It enables them to focus on their health and wellbeing from the point of diagnosis and be supported engaging in positive behavior changes.

In June 2019 a cancer patient focus group was held to review the health and wellbeing offer available at CHFT and to introduce the concept of Prehabilitation to facilitate and gather patient's perceptions, experience and feedback. The main theme that evolved suggested that patients felt the health and wellbeing sessions were beneficial but offered too late in their cancer journey, only being available at the end of treatment. Furthermore, they felt the offer of Prehabilitation, coupled with a Health and Wellbeing Session for patients on diagnosis would be a beneficial support mechanism offering relevant advice and education at the beginning of their journey.

The Cancer Team, comprising of the Prehabilitation Lead, Lead Cancer Nurse, Macmillan Information Centre Manager, with support from the Dieticians and Clinical Psychologist developed an information and education session to deliver to patients on diagnosis; "First Steps". The 3 hour session aims to provide patients with a "light touch" health and wellbeing information and education session based on the key principles of Prehabilitation, the Macmillan Information and Support Service and the clinical aspects of their treatment. The sessions currently run monthly however it is expected that as demand increases the sessions will be offered fortnightly. There are approximately 3500 patients diagnosed with cancer at CHFT each year; thus potentially 291 patients per month accessing our health and wellbeing cancer programmes which include the on diagnosis First Steps session. This then supports the outcome of potentially reaching more cancer patients and increasing the offer of universal support available.

The graphs below demonstrate figures for attendance, timing between diagnosis and attendance, and the prevalence of patients from different cancer sites.

**First Steps attendance figures:**

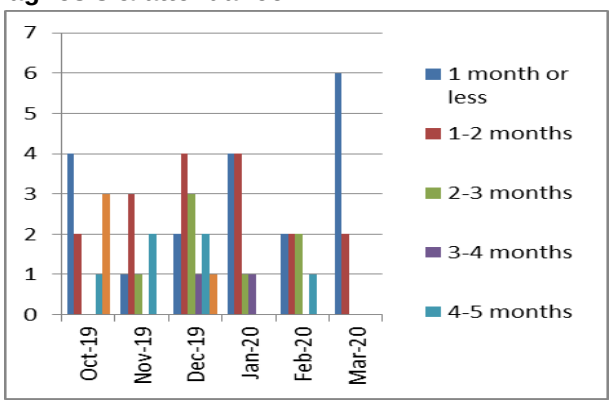



| Month | October 2019 | November 2019 | December 2019 | January 2020 | February 2020 | March 2020 | Total |
|---|---|---|---|---|---|---|---|
| Total No. of attendees | 18 | 10 | 18 | 17 | 13 | 13 | 89 |
| No. of patients | 10 | 7 | 13 | 10 | 7 | 8 | 55 |
| No. of relatives / carers | 8 | 3 | 5 | 7 | 6 | 5 | 34 |

The number of people attending the sessions has been varied. This has been discussed at the prehabilitation project steering group to explore reasons for the low uptake. Potential reasons included staff promotion, timing of the session being too close to or after the start of a patients treatment / surgery and potential environmental and social barriers to attendance. It was also felt that this was a new health and wellbeing offer which would require time to embed. Alternative options for promoting First Steps were suggested, agreed and tried; a formal appointment letter issued to the lung and gynae cancer patients, more publicity regarding the session around the hospital sites, increased awareness to clinical staff with flyers in clinic rooms to ensure they invited their patients to attend. A questionnaire was also issued via Survey Monkey to patients who had volunteered their email addresses to obtain feedback about their awareness of and attendance at the sessions.

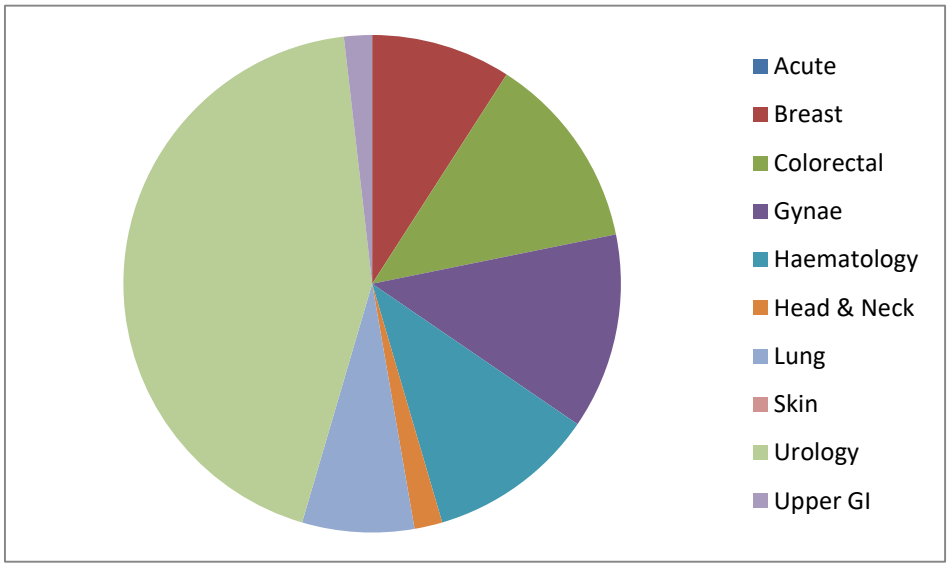
Over the six sessions between October 2019 and March 2020 there were 89 people who attended in total, 55 patients and 34 relatives/carers. Despite numbers being lower than expected, it was felt the format and offer would remain the same as feedback from those that did attend was very positive. More effort would be placed into the promotion and value of the sessions and the offer of inviting clinical staff to observe a session to fully embrace the offer and value we were seeing for their patients.

**Length of time between diagnosis & attendance:**




The figures in graph 2 highlight the time between diagnosis and attendance. As time went on this time lapse reduced, capturing that more patients were being offered attendance at the session closer to their diagnosis and were attending prior to the start of their treatment. It is felt that as the clinical staff become more familiar with the programme there will be higher attendance and closer to a patient's diagnosis.

**Attendance per cancer site:**




Graph 3 highlights the tumour site of those patients attending First Steps. Urology patients being the highest in attendance and Upper GI patients being the lowest proportion. It is unclear as to the rational behind this and when explored with clinical staff was felt the urology clinical nurse specialists were very proactive informing their patients of the sessions and the potential benefits of the support offered.

Patient feedback

Thirty-eight evaluations were completed by patients on the day. Overall the feedback was positive with everybody highlighting some value to them and what they were going to do as 'next steps'. Feedback was also gained on improvements that could be made which we have considered in the planning of future sessions. See Appendix 1 for the feedback results.

Survey Monkey questionnaire

To gain more feedback and an insight to the lasting benefit of first steps a questionnaire was sent out to patients who had previously attended First Steps who had agreed to be contacted by email. Twenty-three surveys were sent out with only five responses. See Appendix 2 to view the survey responses.

Patient comments

*"Wish I had this course when I had a diagnosis of cancer 2 years ago, this is my second episode".*

*"I took the number of the lady next to me-we have the same cancer & this for me is priceless to be able to talk to someone going through the same thing",*

*"Really helpful to have information given verbally, felt personal".*

"*The four weeks since my partner's diagnosis have felt like a real abyss – as if we have been in complete darkness, not knowing what to do or where to turn. What you have done this morning in First Steps is to shine a light on the path ahead – you are all pathfinders – and we are very glad we came".*

*"It was good to meet people in the same situation as yourself and all of the speakers and nurses were excellent. I think a longer session would be good as the speakers seemed a little rushed and more time for discussion would be useful."*

Smoking cessation

Smoking causes 16 different types of cancer and is the single biggest avoidable risk factor and 1:8 cancer cases are caused by smoking and causes 27% of all cancer deaths in the UK (Ash, July 2017).

In West Yorkshire smoking rates are above the national average at 18.6% and lung cancer is the most common cancer across West Yorkshire, (West Yorkshire and Harrogate Cancer Alliance). Figures from Public Health England show that Calderdale has a better than average quit rate. Calderdale remains part of the Yorkshire Smoke Free service and this has been commissioned for a further two years.

In Kirklees 1 in 5 adults smoke; a decrease from 1 in 3 in 2005, (kirklees.gov.uk). Kirklees smoking cessation services are offered through pharmacies and GP surgeries.

The lung cancer clinical nurse specialist team has completed training to provide smoking cessation support to their patients and are non-medical prescribers to support patients with Nicotine Replacement Therapy.

Of the eleven patients participating in prehabilitation six were smokers at the point of diagnosis. All of the patients successful stopped both with and without nicotine replacement therapy however all rceived support from the lung cancer clinical nurse specialists. Four were Kirklees residents, two were Calderdale residents.

Smoking cessation is an important part of a person's general health and wellbeing. Research shows the benefits of stopping smoking when preparing for treatment and surgery can improve outcomes. Prehabilitation includes the smoking cessation and supporting people stop prior to treatment starting.

The prehabilitation lead has worked closely with the Kirklees CCG staff and Yorkshire Smoke Free (YSF) Calderdale service in sourcing what support is available for patients in the local community. As a result of this YSF Calderdale now attend the First Steps health and wellbeing programme and provide a short presentation regarding the benefits of stopping smoking, the benefits to optimising health and outcomes after treatment and surgery. They also support patient's relatives and carers.

Targeted and specialist Prehabilitation (objective 4 & 5)

With adequate screening tools in place there is the ability to determine which patients require more targeted and specialist Prehabilitation interventions.

Targeted Prehabilitation applies to those people with cancer who have other pre-existing or long term conditions that affect their function. This is approximately 30% of the population, (NHSE Comprehensive Model for Personalisd Care, 2019)

Specialist Prehabilitation applies to those people with cancer who have more complex acute or chronic needs with severe impairment, that are difficult to control, and patients have lower levels of function, mood and confidence. This equates to approximately 5% of the population, (NHSE Comprehensive Model for Personalisd Care, 2019).

Due to their ongoing health needs, this cohort of patients may find it difficult to engage in services and interventions, be harder to reach and at higher risk of not receiving primary treatment or being able to withstand the effects of treatment and subsequent recovery.

Many of these patents can be identified when seen at their initial appointment with the clinician. Currently some formal measures are in place, such as the WHO performance status classification, Charlson Comorbidity Index, Frailty scores, height/weight/BMI, Pulmonary Function Tests. Taken into consideration, along with specifics of their disease/cancer diagnosis, these may then indicate a patient's risk level, potential suitability for the variety of treatment options available and potential areas for improvement. Patients who are higher risk would then require a more targeted and/or specialist Prehabilitation care plan (see appendix) and interventions. The outcome measures, explained earlier, are recognised by some of the services providing prehabilitation interventions to patients in the community and most of the acute services available.

Currently patients of higher risk are identified by the clinicians within the Lung and Gynae cancer MDT and are subsequently being seen by the Prehabilitation Project Manager in an appointment clinic following diagnosis. The outcome measures are used to identify baseline function / performance and specify the area of patient need and to what level. Not all patients will require all interventions and first line support and advice may be adequate for some of the prehabilitation components. Where targeted and specialist support and interventions are required a Prehabilitation care plan is created together with the patient ensuring it takes into account all aspects of personalised care.

Interventions suitable for higher risk patients need ideally to be provided by registered practitioners. In some instances, specifically physical activity interventions, activity needs to be supervised and patient's physiological response to treatment measured and monitored closely.

The recent emerging evidence and Principles and Guidance for Prehabilitation within the management and support of people with cancer, 2019, offer guidance on the required workforce to provide safe and effective Prehabilitation interventions. They advise:

- Screening and monitoring should be carried out by registered health professionals or by unregistered professionals through a supported delegation method.
- Universal interventions may be self-delivered or provided by any health care professional.
- Assessment and prescription of targeted and specialist interventions should be undertaken by registered health care professionals.
- Targeted interventions may be delivered by registered health professionals or by unregistered professionals through a supported delegation method.
- Specialist intervention should be delivered by registered health professionals.

The project to date has highlighted that there are limited resource and services available to provide supervised interventions for physical activity with higher risk groups. Currently the council leisure facilities have 1.5 WTE level 4 personal trainers with knowledge of cancer. The

overall population of those requiring targeted and specialist support is lower however it is felt a greater array of opportunity for patients is required. Not all patients, especially those who do not ordinarily participate in physical activity, may feel comfortable accessing a gym / fitness class. CHFT and Locala (NHS community healthcare provider in Kirklees) provide pulmonary rehabilitation courses to patients with COPD. Pulmonary rehab is offered to patients with lung cancer in some areas across the country with benefits being seen for patients before their cancer treatment and as part of the rehab continuum. The prehabilitation lead visited Rotherham Breathing Space, (provider of pulmonary rehabilitation in South Yorkshire) to explore this further and presented the idea to the Advanced Practitioner in Respiratory Physiotherapy and the Clinical Lead Physiotherapist for the CHFT pulmonary rehabilitation group (PRG) and it was agreed to trial attendance at the PRG for lung cancer patients who live in Calderdale (CHFT community services available to Calderdale residents only). To date only one patient attended, a total of 6 sessions and this was cut short due the corona virus pandemic. Therefore, evaluation of this was not achievable.

It is therefore suggested the use of PRG as a provider of supervised exercise intervention, to those higher risk lung cancer patients, be trialed again when and if services resume.

<u>Personalised care</u> (objective 7)

The NHS long term plan (2019) describes how a 'one size fits all' provision of health and social care cannot meet the needs of people, especially those with varied and complex needs. It aims to ensure people have more choice and control over their care and states that, by 2021 'where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support, all delivered in line with the Comprehensive Model for Personalised Care'

To ensure the prehabilitation project is person centred, all patients have a personalised prehabilitation care plan (see Appendix 2). This encourages patient engagement in ensuring prehabilitation plans underpin and include what matters to them as an individual. This ensures plans are person centred with interventions agreed to increase their physical activity, improve nutritional intake and manage emotions is individual and meaningful to them. This improves adherence to the plan thus improving function and aims to improve overall outcomes.

To achieve personalised care the project includes the use of the NHSE six personalised care questions, 'what matters to me'. This enables the project lead to first get the patient to start to think about their lives, what's important to them especially now around the time of a cancer diagnosis and forthcoming treatment. Some of this information is vital to developing a plan which incorporates who and what is important in their lives and routine. It also enables health care professionals to gain a greater understanding of the patient to ensure care is what the patient wants, they have a greater choice in the decisions being made and are not 'done to'. This is completed at the first assessment and uploaded to the patient's electronic health care record so is accessible to all staff caring for that patient.

The project also incorporates the Patient Activation Measure (PAM). A tool designed to understand a patient's confidence, knowledge and skill in being able to manage their health conditions. The PAM supports prehabilitation in tailoring support and interventions to a patient's needs; identifying how much knowledge the patient may have around their health and wellbeing, the information they need at the point of diagnosis to support them getting to and through their treatment and in what format the information, education and support may be required. It identifies whether and what additional support they may need to participate in activities and interventions for example using a step counter, fitness tracker, heart rate monitor when participating in physical activity. It then determines how confident they feel they can make changes and sustain them, and the level of support initially required to achieve this. This has enabled the project lead to determine who requires weekly follow up / motivational calls and who

requires more or less frequent. Who has the activation level to require 'light touch', first line / universal prehabilitation offered through the first steps information and education sessions to then support themselves to and through treatment with touch points as required and those who require much more of a support plan with the potential of offering more one to one support, for example through the use of social prescribers.
The use of the PAM with all cancer patients is also being considered following its use with Prehabilitation. The use of the PAM in obtaining an activation level at the beginning of a patient's cancer experience can also support the healthcare professional when looking to their recovery and personalised stratified follow up. Understanding a person and how they react to certain situations regarding their health and how they can support themselves is essential when planning stratified follow up.
The use of the PAM tool with all cancer patients can also support how service provision is focused and identify if there are demographics of patients or tumour site specific patients who fall within similar activation levels to then determine the support they require which may differ from others.

'What matters to me' when formulating Personalised Care plans, case examples -
When Shamime completed the 'what matters to me' questions her friend Joyce featured in most of her responses. It was clear from this that Joyce was what mattered to her most, she saw her every day and being unable to spend time with Joyce would be difficult and cause a certain level of distress.
Shamime also completed the Patient Activation Measure and was level 1 – disengaged and overwhelmed. Knowing this information about Shamime and that additional support would likely be required due to her low activation level, this enabled a personalised prehabilitation care plan to be completed which featured her friend Joyce as being integral to this plan, being there to support her engage in meaningful activity that would prepare her for her forthcoming cancer treatment. Joyce would be there to motivate and support her complete the physical activity goals she had set, encourage her with healthy eating and provide the emotional support that she may need as she went through cancer treatment.

When Dave was diagnosed with cancer he completed the 'what matters to me' questions. Aside from his family, Dave loved his dog. He spent time out walking his dog, and even mentioned his dog followed him everywhere he went…even the loo! A bad day for Dave would be not being able to take his dog out for a walk. When completing his personalised prehabilitation care plan, his dog became the focus, increasing his physical activity levels by walking with his dog for longer, walking further and increasing intensity taking on some hills. The relationship he has with his dog was also taken into consideration when Dave started treatment, and with support he was able to pace himself and grade activity to ensure he was still able to get out with his dog and maintain some level of physical activity during his treatment. A personalised rehabilitation care plan was then created, again using the focus of his dog, as he increased physical activity levels during recovery and regaining his pre-treatment level of function.

## Section 5 Equality and diversity assessment of the service

The Universal, whole population approach of prehabilitation has been made available to all newly diagnosed cancer patients across all cancer sites within the organisation through the provision of First Steps cancer programme. At present those attending the First Steps information and education sessions which provide the information and support at the start of their cancer journey have been a widespread representation of age groups across the population. There has been little uptake in attendance from patients of different ethnic backgrounds; 82% of attendees were white British, 15% white other, 3% mixed white / Asian. The development of delivering elements of First Steps in other formats may support more patients having access to this, for example, electronically. Reaching the communities, that we know are diagnosed with cancer, that are not accessing information and support on diagnosis, is something that can be explored further with support from the Macmillan Information and Support Service when attending Outreach Events within the 'hard to reach' communities and through support of our BAME forum.

Of the 55 patient's that attended 29% were Calderdale residents and 71% were Kirklees residents. The events are held at Huddersfield Royal Infirmary as access, parking and room availability is easier on this site, it may be that there is a higher prevalence of Kirklees residents attending due to the location of the event.

Eighty-two percent of the prehabilitation project patients were white British, with 9% Pakistani and 9% white other

The promotion of prehabilitation and the project across the wider partner organisation is a way of sourcing more information, support and awareness to patients through their local GP and community health resources. The awareness within the Social Prescribing services and networks can also increase recognition of the project and develop systems and approaches to support people in harder to reach communities and with those of lower activation and engagement levels.

## Section 6 Activity analysis

To March 2020 the project has had fourteen patients that have taken part in the Prehabilitation process; twelve patients with lung cancer and and two with gynaecological cancer. Eleven patients had assessments with prehabilitation care plans created and three were supporting the project in the initial stages to review the use of specific screening and assessment tools.
Five out of the eleven patients were ex-smokers; the remaining six were current smokers and had lung cancer. They were being supported to quit with the help of the lung cancer clinical nurse specialists. Tumour staging varied across the staging parameters. Nine patients were being treated with curative intent and two were palliative. Four patients have sadly died.
The WHO performance status classification is a measure of how well a person is able to carry on ordinary daily activities while living with cancer, and provides an estimate of what treatments a person may tolerate. The levels range from 0-5;

- 0 being Asymptomatic (Fully active, able to carry on all predisease activities without restriction),
- 1 – Symptomatic but completely ambulatory (Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature. For example, light housework, office work)
- 2 – Symptomatic, <50% in bed during the day (Ambulatory and capable of all self care but unable to carry out any work activities. Up and about more than 50% of waking hours)
- 3 – Symptomatic, >50% in bed, but not bedbound (Capable of only limited self-care, confined to bed or chair 50% or more of waking hours)
- 4 – Bedbound (Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair)
- 5 – Death

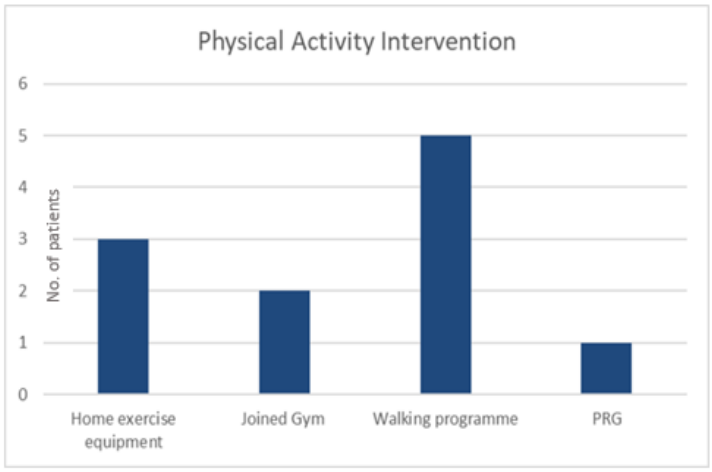
The performance status of the prehabilitation patients ranged from 0-2 (see chart below).

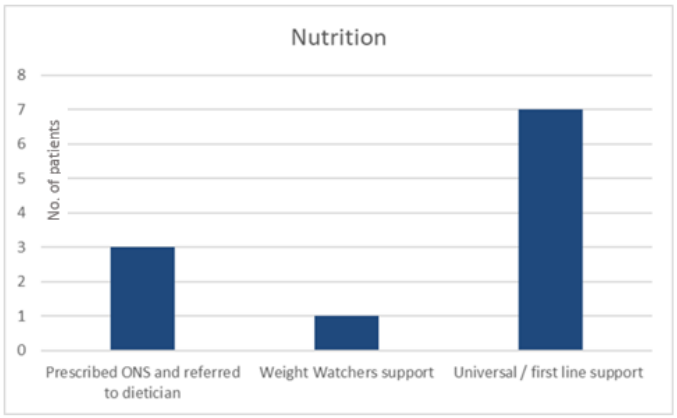

The eleven who participated with prehabilitation care plans created all received universal prehabilitation support, which offered first line advice covering all prehabilitation components; physical activity, nutrition, psychology and smoking cessation. All patients were seen with a relative or friend present, enabling them to hear the advice being given and support offered and provided for them if required, as their key person supporting somebody with cancer.

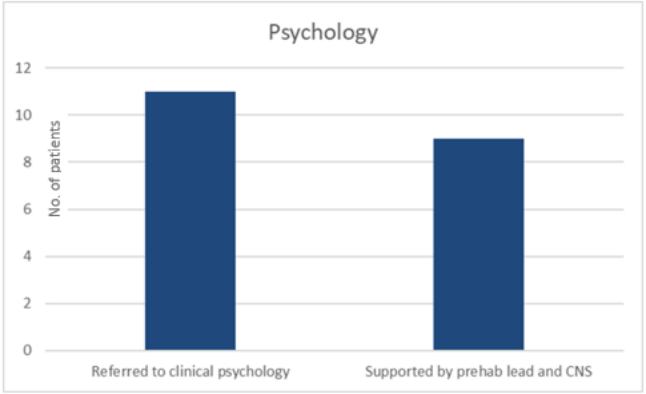
The Patient Activation levels of the eleven patients varied across the 4 levels as shown in the table below:

| Level 1 - Disengaged & overwhelmed | Level 2 - Becoming aware but still struggling | Level 3 - Taking action & gaining control | Level 4 - Maintaining behaviours and pushing further |
|---|---|---|---|
| 3 | 2 | 4 | 2 |

The following graphs show those who participated in one or more specific interventions and what they were:



Of the eleven patients four were reassessed prior to their treatment starting and the other 10 weren't for reasons broken down in the table below. Other reasons for not having a re-assessment were progression of disease, staff capacity, availability of carer and the Coronavirus

| | | |
|---|---|---|
| Reassessed | Reassessed | 4 |
| Not Reassessed | Didn't adhere to plan | 1 |
| | Declined | 2 |
| | Other | 4 |
| | Trial of screening and assessment tools | 3 |

All four patients that had a reassessment were lung patients. Two were ex-smokers and two had continued to stop smoking with nicotine replacement therapy and support from the nurse. All four had a WHO performance status classification of 1.

The Patient Activation level of the patients varied with two patients having an activation level of 2, one had a level 3 and the remaining patient had a level of 4. All patients received the same level of support from the prehabilitation lead throughout with a weekly motivational telephone call and access to the prehabilitation lead for support as and when the patient required in between times.
The patient who did not adhere to the prehabilitation care plan or engage in any of the interventions, despite the plan being personalised to her at a level which was appropriate, was an activation level 1. Raising the question of the level of support required for these patients to engage and exploring futher if there is any possibility of engaging level 1, low activation patients at this time.

The outcomes for all four patients were favourable following participation in prehabilitation prior to their cancer treatment. All had increased their level of physical activity which reflected in their increased walking distance on the incremental shuttle walk test. Two of the patients had increased their weight and two had lost weight which was their intended outcome. Those with higher anxiety and depression scores had lower scores and lower highlighted concens on reassessment.

## Section 7 Levels of Intervention or dependency

The First Steps programme, offering universal prehabilitation to all newly diagnosed cancer patients, is delivered monthly and lasts for approximately three hours. There are four members of staff presenting at the session; Lead Cancer Nurse, Prehabilitation Lead and the Macmillan Information Support Service Managers. It is felt the demand upon the staff to deliver this programme is acceptable given the reach to the wider cancer population accessing services within the organisation. The potential impact of this is the reduction in demand on clinical teams for enquiries and support from patients before and during the cancer journey as patients have been forearmed with information and the first line level of support with a personal approach to empower the patient to support themselves as much as possible and provide them with links and signposts to further information and support if required.

The initial prehabilitation assessment for a patient, to complete the assessments and create a prehab care plan, with the prehab lead takes approximately 60-90 minutes. The level of intervention very much depends upon the identified needs of a patient and if they require support with all components of prehabilitation. The session allows for there to be meaningful conversations with patients and their relatives and for the prehab lead to provide first line support and advice in helping address some of their concerns and make recommendations of how to support themselves going forward.
Following the initial assessment and creation of a prehabilitation care plan the ideology is that patients are emto follow their plan and engage in agreed interventions independently. The prehab lead has then been providing weekly follow up phone calls to provide support, motivation and assist with any concerns they may have. Patients appear to appreciate the call and the data demonstrates how all except one patient engaged in prehab interventions despite the activation level.
The follow up appointment, prior to treatment, to reassess progress made, using the outcome measures takes the prehab lead around 30 minutes.

To support the clinical nurse specialists, avoid patients having duplicate conversations about concerns and to avoid additional visits to the hospital the prehabilitation lead has been incorporating the Macmillan Holistic Needs Assessment into the prehab assessment. This also supports the potential for elements of prehabilitation and conversations to be embedded in the future as part of the HNA. This then opens up the opportunity for the nursing staff, when completing an HNA with patients, to create a prehab plan in the lead up to treatment.

Following treatment and surgery patients are then reviewed by the prehabilitation lead to establish a rehabilitation plan and support patients in the positive behaviour change they have made going forward.

Further exploration is required of those patients with lower activation levels and the demand and dependency this may involve to support the patient engaging in prehabilitation interventions.

## Section 8 Case studies/Service user stories

Colin's story – Colin was diagnosed with lung cancer and the plan was to treat radically with curative intent. Colin was keen to participate in prehabilitation and to be as prepared, as much as possible, for treatment. The initial prehabilitation screens and assessments, along with the personalised care tools highlighted that Colin wasn't meeting the CMO physical activity guidelines, had a high BMI, and was anxious about the prospect of surgery as the treatment option.

Colin was keen to be more active and agreed to join a gym and use a static exercise bike at home. A referral was made to the level 4 personal trainer in Calderdale to support Colin with an exercise plan he could participate in at the gym. Colin also committed to using the exercise bike every day for 30 minutes – some days broken down into two sessions.
He was keen to lose weight and felt increasing his activity levels and having a balanced healthy diet would be adequate to support this. From a psychological perspective he was concerned about what the treatment would entail and whether he could mentally cope and proceed with treatment. His anxiety and depression score were high therefore a referral was made to the into the cancer clinical psychology service.
Colin completed 5 weeks of prehabilitation; maintained activity levels and engaged in clinical psychology. His outcome measures at reassessment had all improved. The treatment plan was for Colin to have thoracic surgery however was felt to be high risk when discussed at the Leeds high risk MDT meeting. Through further team discussions and taking into account his participation in prehabilitation, improved outcome measures and his confidence to proceed with surgery as his choice of treatment, influenced the decision to proceed with the surgical option. Surgery was successful and once discharged by the surgical team at his 6 weeks review he re-commenced gym attendance. He then had a course of Chemotherapy treatment, during which time he continued attendance at the gym and using his exercise bike. Colin is now cancer free…*'prehabilitation helped to reduce my anxiety and gave me more confidence, yes, I would recommend prehabilitation to others, it answered all my questions and concerns and gave me relevant advice in a professional and friendly manner'*

Ray's story – Ray was diagnosed with lung cancer and the treatment plan was to radically treat with curative intent, with a course of concurrent radiotherapy and chemotherapy.
Ray was also keen to participate in prehabilitation and would say 'there's nothing wrong with me, I just have cancer and with the right support I can fight this'. Baseline measures and assessments were completed. Ray wasn't as active as he'd like to be and for him feeling strength through being active was important. He had a healthy weight and his psychology screen highlighted some low-level anxiety and depression levels.

Ray completed 3 weeks of prehabilitation. His physical activity intervention was a home-based exercise programme using a static exercise bike and walking every day. He was given support with managing emotions from the prehabilitation lead through talking about how he was feeling and ways he could manage these. After the three weeks of prehabilitation Ray's outcome measures had improved. His improved level of fitness is demonstrated in his shuttle walk distance, his anxiety level improved and his weight increased allowing for any potential weight loss or change during treatment. Ray went on to have 4 weeks of concurrent chemotherapy and radiotherapy, having weekly support calls from the prehabilitation lead.

Ray was managing to continue to exercise and eat well through treatment with very little side effect reported, just slight fatigue the day following the dose of chemotherapy.
Ray didn't make it to the end of treatment as he contracted Coronavirus and sadly died, peacefully at home a week later.

## Section 9 Evidence impact of service

Outcome measures have been used to identify baseline function and performance of patients at point of diagnosis with a review and reassessment following a period of prehab and prior to a patient's treatment. The data has been positive in demonstrating improvement in patient's physical fitness, emotional wellbeing and weight management.

At this point of the project there is only a minimal data set due to unforeseen circumstances hindering the reassessment of patients.
Below are two sets of quantitative data to demonstrate improvement in a patients outcome measures following a period of prehabilitation.

This table demonstrates Colin's baseline and re-assessment measures –

| | **Baseline** | **Re-assessment** |
|---|---|---|
| **Patient Activation Level:** | 4 (score 84.8) | 4 (score 80.9) |
| **PG-SGA:** | Stage A | Stage A |
| **Weight:** | 108kg | 106kg |
| **Height:** | 165.5cm | 165.5cm |
| **BMI:** | 39.6 | 38.9 |
| **GAD-7:** | 12 | 7 |
| **PHQ-9:** | 12 | 5 |
| **IPAQ:** | <150 minutes p/w | >150 minutes p/w |
| **Incremental Shuttle Walk Test:** | 210metres | 280metres |

This table demonstrates Ray's baseline and re-assessment measures –

| | **Baseline** | **Pre-treatment re-assessment** |
|---|---|---|
| **PAM Level:** | 3 (70.2) | To be repeated at 3 months |
| **PG-SGA:** | Stage A | Stage A |
| **Weight:** | 74.8kg | 79.4kg (↑5kg) |
| **Height:** | 181.5cm | 181.5cm |
| **BMI:** | 22 | 24.2 |
| **GAD-7:** | 3 | 1 |
| **PHQ-9:** | 3 | 3 |
| **IPAQ:** | Active but <150m p/w | ↑Activity level 150m p/w++ |
| **Incremental Shuttle Walk Test:** | 420metres | 520metres |
| **Grip strength:** | 44.6kg (R) | 48.6kg (R) |

The data above demonstrates that patients' needs are being met and that the period of prehabilitation and interventions being used are of benefit to patients in improving their function and wellbeing prior to cancer treatment. In the instance of Ray who increased weight, this was seen as a positive outcome due to the potential weight loss he may experience during treatment. It could also demonstrate an increase to muscle mass following the increased levels of exercise.

Two further patients who were undergoing surgery were initially considered too 'high risk' to undergo surgery. Following a period of prehabilitation they both objectively improved their fitness and resilience enabling them to undergo planned surgery without complications.

The patient who participated in the Pulmonary Rehab Group, which was halted early in his prehabilitation due to the Corona Virus pandemic, sadly didn't have the same post-surgical result. He was at higher risk having had lung surgery in the past which had required intubation on intensive care. Following his lobectomy, he had a prolonged stay on intensive care again and sadly died after suffering a cardiac arrest.

The success of pulmonary rehabilitation as a prehabilitation intervention for patients after lung cancer surgery has been seen in Rotherham, South Yorkshire at their Breathing space programme (*Is Pulmonary Rehabilitation appropriate and beneficial for patients after surgery for lung cancer? A service evaluation of outcomes. Martin K, et al. Journal of the Association of Chartered Physiotherapists in Respiratory care. 2016*) in supporting patients prior to lung and colorectal surgery for cancer. However, it is felt this requires further exploration and testing at CHFT as and when this is re-established following the Corona Virus pandemic.

## Section 10 User feedback

Evaluation forms were completed at the end of each First Steps session and the feedback can be reviewed on page twelve of this report. The survey results obtained after attendance at the First Steps programme can also be found on page twelve.

Individual patient feedback from First Steps:

“The four weeks since my partner’s diagnosis have felt like a real abyss – as if we have been in complete darkness, not knowing what to do or where to turn. What you have done this morning in First Steps is to shine a light on the path ahead – you are all pathfinders – and we are very glad we came.” Attendee Nov 2019.

“The whole morning was excellent and very informative, especially finding out about what support is available.” Attendee October 2019.

“It was good to meet people in the same situation as yourself and all of the speakers were excellent. I think a longer session would be good as the speakers seemed a little rushed and more time for discussion would be useful.” Attendee October 2019

“Hearing Rob’s story was really helpful - he was fantastic and gave me hope that there will be light at the end of the tunnel.” Attendee December 2019


Rob, one of the patient reps, sharing his story at First Steps

**Staff and colleague feedback:**

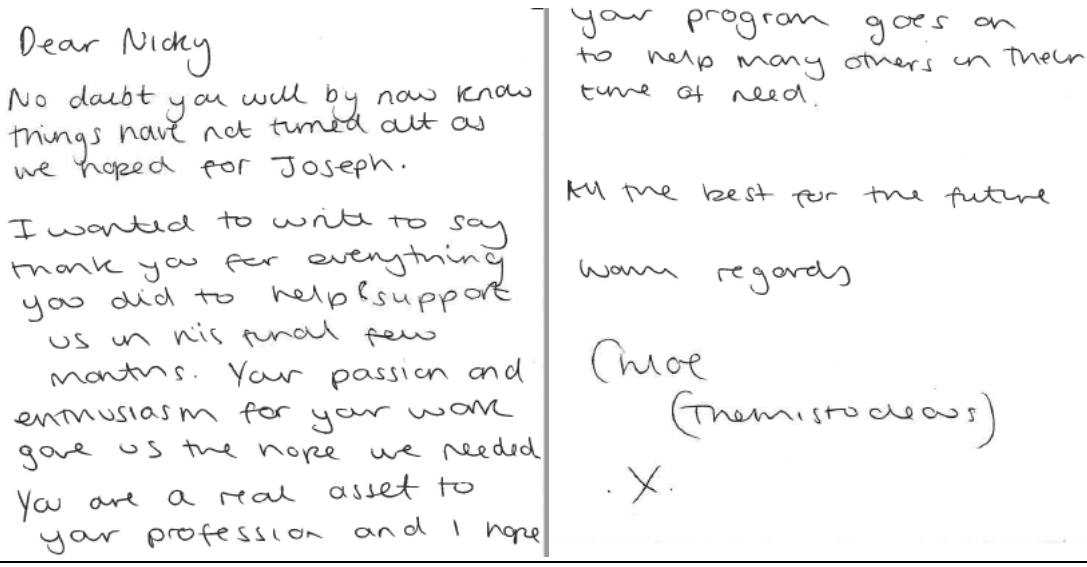
“It has been a huge privilege to work closely with Nicky Hill, our Macmillan Prehabilitation Project Manager this last year. The collaboration with her, our Macmillan information team and the lead cancer nurse, led to the development of First Steps - a new and pioneering information and support session for recently diagnosed patients in our trust. First Steps has enabled patients to feel supported from the outset and has set an agenda of self-supported management, highlighting the importance of physical activity/diet and empowering patients to take control.
Nicky has also demonstrated great networking skills - actively engaging with many varied staff

in the community, and then often linking them with our service too. Not only is she passionate, hardworking, patient centred and well organised, but she has made a significant difference to patient outcomes and experience by establishing a prehabilitation pathway and interventions in our trust, in a relatively short space of time". Helen Jones, Macmillan Information Service Manager.

<u>Prehabilitation project patient feedback</u>:

'Thank you for your time and effort you have put in to address the issues I had.
It feels like it's the first time someone has actually been clear about anything I've asked, and I really appreciate it. I feel like I've struggled knowing what to do and when to do it and because I haven't fit the general category of people who have gone through this it's been difficult to get any kind of personalised or individualised input. Once again thank you for your help and advice Nicky'. Lung Cancer patient.

Card received from a patient's daughter-


Dear Nicky

No doubt you will by now know things have not turned out as we hoped for Joseph.

I wanted to write to say thank you for everything you did to help & support us in his final few months. Your passion and enthusiasm for your work gave us the hope we needed You are a real asset to your profession and I hope your program goes on to help many others in their time of need.

All the best for the future

Warm regards

Chloe
(Themistocleous)

. X .

## Section 11 Other service activity

Over the past year the project lead has been involved in setting up a virtual prehabilitation network over email to link others interested in and developing prehabilitation in the areas in which they work. It provides a forum in which we can share ideas and resources, update each other on progress with our projects and provide professional support. The project lead is also part of the north west and wales Prehabilitation group.

The prehabilitation lead has written blogs and case studies for Macmillan and NHSE promoting the benefits of prehabilitation, the project progress and how personalised care is being implementation with the use of the 'what matters to me' questions and the PAM and how they are benefiting cancer patients at CHFT. The project lead has also presented the work done to date regarding personalised care at a study day in Leeds hosted by NHSE.

The project lead also sits on the Smoke Free CHFT group to support the trust becoming completely smoke free by June 2020 (delayed due to the Corona Virus pandemic). This supports the smoking cessation promotion and support offered to cancer patients and their relatives within the prehabilitation project.

The project lead collaborated with both local the hospice organisations to develop information and advice regarding physical activity during chemotherapy and radiotherapy. A comment was made by a patient at a health and wellbeing event that she had stopped exercising during treatment and asked the question when could she start again? This led to discussions around supporting these patients and their clinicians in what to advise. With the support from the therapists at Guys and St. Thomas' hospital London, this information was adapted for our use and is now available for our patients undergoing chemotherapy and radiotherapy and is included in the chemotherapy unit pre-assessment packs as well as First Steps and is on the Trusts document repository.

Leeds Teaching Hospitals Trust is running a project to improve and optimise patients from a medical perspective before they have surgery for gynaecological cancer, including the management of anaemia and other co-morbidities. The prehabilitation lead has been involved in the prehabilitation of two of the patients from CHFT that went to Leeds for surgery to improve their health and well-being and supported the clinical nurse specialists in education and signposting patients to the First Steps health and wellbeing programme.

The project lead has liaised closely with an exercise physiologist at the University of Huddersfield to explore increasing their offer of exercise classes to patients who are affected by cancer. They currently offer one session a week to ladies who have had breast cancer following the success of this through a PhD research study. They are now considering opening this up to become a ladies only class for any woman having had cancer. They also provide a mixed class are considering offering 'men only' classes too. The project lead connected the exercise physiologist with our Macmillan Information and Support Service manager which has led to his involvement in the delivery of the physical activity component of the Thinking Ahead health and wellbeing programme for people living with incurable cancer.

## Section 12 Learning and development

Over the past 12 months the prehabilitation lead has had a wide variety of opportunity for learning and development in relation to managing the project and developing knowledge of Prehabilitation with cancer patients. Much of the learning has been undertaken through opportunity with Macmillan.

- Macmillan Calderdale Framework AHP event – Service Needs Analysis workshop
- Macmillan Calderdale Framework event – tasks analysis workshop
- Macmillan Induction day
- Macmillan Calderdale Framework validation event (London)
- Macmillan Emotional Support Idea Generation Workshop
- 3rd EBPOM International Prehabilitation Conference attendance & launch of prehabilitation guidance document (London)
- West Yorkshire & Harrogate Cancer Alliance (WY&HCA)- Living with a palliative diagnosis workshop (Leeds)
- Macmillan Introduction to Evaluation study day
- Royal College of OT, HIV Oncology & Palliative Care, specialist section palliative care & palliative rehab network day
- Health Education England - Transforming our Workforce Conference, Leeds
- Macmillan Professionals Annual Conference - Birmingham
- Developing and Implementing Service Improvement Projects (Macmillan) Leeds
- Evidence into practice: Audit to improve patient care, e-learning module
- Make Every Contact Count e-learning modules completed.

In addition to formal courses and training the prehabilitation lead has been involved in and attended local and regional prehabilitation networking forums to share and learn from each other and provide support where necessary.

Future learning and development needs remain around the development of project management skills through a formal certified qualification. The project lead has applied for a Macmillan education grant with support from CHFT to enrol onto the Managing Successful Programmes course, with the aim of completing this in September 2020. It is felt that having this formal certificate and training will support the project lead in the final part of the project, support any future plans with the project and further career progression in the field of service improvement, development and project management.

## Section 13 Conclusion

The project is supporting the message to patients, their families and staff about the benefits of prehabilitation; being active, having a healthy diet, psychological wellbeing and positive behaviour change when diagnosed with cancer in preparation for treatment and beyond. It is also supporting the offer of information and education to patients, about how they can retain control, be involved in decision making and support their health and wellbeing.

The universal element of prehabilitation is now established in CHFT through the offer of the First Steps Health and Wellbeing programme and is a huge achievement for the project and the Trust. Supported by the Lead Cancer Nurse and Macmillan Information and Support Service in its delivery, this will remain a focus over the coming year to optimise this and support clinical teams using the Macmillan HNA to promote patients to access First Steps and provide first line advice and education to their patients. Ongoing work will include supporting staff have better conversations with patients, to personalise their care, and provide education and training in this area for staff to achieve this.

The objectives, for the first year of the project, have been referenced throughout the report, with those having been achieved continuing to have a level of focus to ensure support available to sustain them and continue to develop where appropriate.

There have been challenges during the first year; engagement due to low staffing levels in teams, the corona virus pandemic, capacity of the project manager. The lung cancer clinical team have engaged well in the prehabilitation pathway for their patients and therefore featured prominently. The gynaecology team have also embraced prehabilitation with their patients. Work has commenced to embed the universal element of prehabilitation with all the cancer clinical teams supporting the first line advice, referral pathways and promotion of the health and wellbeing programme. Ensuring we are delivering what patients need, for instance further development of smoking cessation support will be required.

One of the intended outcomes of the project is to support more patients get to and through treatment. With the offer of universal health and wellbeing support this will contribute to this however it is felt those not getting to and through treatment are the 40 percent of patients who are in the targeted and specialist population. It is estimated that CHFT diagnose approximately 3500 people with cancer per year. 40% of this is 1400 people. Plans and developments going forward and a primary focus for the project lead now that the universal support is established, will explore how targeted and specialist prehabilitation could be provided, identify who and how many of the 1400 patients would require this level of prehabilitation and ways in which this can be delivered.

As mentioned at the beginning of this report, the offer of universal prehabilitation is being offered with no additional cost to the Trust however, the provision of more specialist intervention will require further service development and potentially additional funding to continue to embed the ethos of prehabilitation in the Trust's service provision. This would support a longer term aim to scale up delivery of targeted and specialist prehabilitation across all tumour sites, across acute and community services, with the potential of an assessment service within the acute cancer services and prehabilitation interventions being delivered by the acute, community and primary care resources. This would also promote partnership working in the provision and delivery of a much more joined up approach of a prehabilitation

to rehabilitation pathway, supporting patients prior to, during and after their cancer treatment.

The corona virus pandemic, with the country entering a phase of lockdown in the final month of the projects first year, has been an added challenge. It meant several of the 'test' patients re-assessments did not take place to fully evaluate the outcomes and benefits to patients. It has also led to group physical activity interventions and other services having to cease or radically change their service offer. However, the pandemic has led to the accelerated offer of virtual support to patients. This continues to be developed to ensure patients continue to be offered the same information, education and support as was being offered face to face.

There is much more that can be achieved within the scope of the project and beyond, in supporting patients from the point of diagnosis in the provision of prehabilitation and enhancing health and wellbeing. The following future plans and targets are described below in more detail to highlight how these will be addressed over the coming year.

## Section 14 Future plans and targets

1. First Steps/Universal Prehabilitation – The development, introduction and initial success of the First Steps health and wellbeing programme in 2019 has been fundamental in the offer of the universal element of prehabilitation to newly diagnosed cancer patients. However, not all patients from different tumour groups are accessing the programme, therefore are missing out on information and education in supporting them prior to cancer treatment. The aim going forward through 2020 into 2021 is to encourage more patients and relatives to access this and for greater endorsement and invitation to patients particularly on diagnosis, from consultants, CNS teams and chemotherapy nurses. Support from the Lead Cancer Nurse in ensuring it is mandatory for staff to invite their patients to First Steps and become part of the patient's care pathway should contribute to increased attendance rates. Clinical staff have been invited to attend First Steps sessions to obtain a greater understanding of the information given to patients and the positive impact this has on patients, this now needs to be an expectation of staff especially Cancer Care Coordinators, who are an integral part of the clinical team and can provide the first line support and advice to patients prior to and through treatment. Further training and education for Cancer Care Coordinators, in the delivery of first line support and advice to patients can also support the delivery of universal prehabilitation within individual clinical teams and can also support those patients who potentially cannot access First Steps. Continuing to collaborate with the Macmillan Information and Support Service, who have been instrumental in the delivery of on-diagnosis support to patients, in expanding, developing and promoting the First Steps offer will ensure the First Steps evolves to meet the needs of patients on diagnosis.

   Smoking cessation is also an integral part of prehabilitation and can be provided through the universal offer. Whilst a local smoking cessation specialist attends First Steps there is a distinct lack of provision within the acute setting. The lung cancer Clinical Nurse Specialists offer this support to their patients in the absence of any wider provision, however other clinical teams do not. It is anticipated that other clinical nurse specialist teams could begin to provide this with additional training and education however; this would potentially increase their workload. As smoking cessation services are available in the community the use of these through consistent referrals would ensure the wider offer to patients with the potential for more positive behaviour change and better outcomes for patients. It is questionable as to whether patients would access smoking cessation services away from the hospital setting. Being cited where patients are having regular appointments and investigations, potentially for the initial assessment with follow up in the community and closer to home may increase positive behaviour change and quit rates among cancer patients and the wider population, thus potentially improving treatment outcomes and reducing overall cancer risk. Within the scope of the project going forward it is felt this area of prehabilitation requires further exploration and recommendation.

2. Upper GI patients – The project has mainly focused upon the lung cancer patients and team due to the engagement of both consultants and nurses with regard to prehabilitation. As this is now established and the lung cancer patients are being given education and advice about preparing for treatment and surgery and offered

support to engage in prehabilitation interventions prior to treatment it is now felt that attention needs to focus on supporting the Upper GI cancer team in developing prehabilitation for the Upper GI cancer patients, who are another group of patients who struggle to get to and through treatment. Engagement has been a particular challenge over the past year as staff have concern their patients are perhaps too frail due to the nature of their cancer therefore would struggle to participate in certain aspects of prehabilitation. In order to demonstrate that despite frailty levels patients can still engage in prehabilitation it is intended that the prehabilitation lead will support the clinical team by providing; education about prehabilitation, how modifications and adaptations to interventions can occur, the benefits, the progress of the project thus far in establishing the universal offer and pathways into services which can support patients. The prehabilitation lead will promote and encourage the universal offer through First Steps attendance and provide support to those patients who need a more individual, tailored prehabilitation plan similar to that given to the lung cancer patients. Attendance at the weekly MDT meeting will enable a greater understanding for both the prehabilitation lead and the clinical team in determining those patients who may require more support prior to treatment. The outcomes can then be shared with the team to demonstrate the value of prehabilitation and the outcomes experienced by patients.

3. Sustainability – Whilst the patients and teams appear to have valued the support from the prehabilitation lead there is potential for the post ceasing to exist at the end of the project. Embedding prehabilitation and the concept of providing specific individual, personalised support to patients upon diagnosis into the wider tumour sites / cancer teams needs to be a focus going forward. The gynae team have been supported during the project by the prehabilitation lead, having also seen gynae patients within the project and offering education and support in how to prepare patients for treatment and surgery, it is felt this needs to be established across the other teams. Links have been made with the chemotherapy lead nurse, urology team, head and neck team, and acute oncology and this now needs to be formalised in enabling them to be able to support their patients in the lead up to and through treatment. The Trust is embracing the use of the Macmillan e-HNA and many teams are looking to provide on diagnosis holistic needs assessments. It is felt this is the ideal time staff can support their patients by offering key messages and supporting patients with positive behaviour change. It is intended the prehabilitation lead, with support from the Lead Cancer Nurse will provide education around the benefits of each of the key elements of prehabilitation, to what level they need to direct their patients, how to advise them in supporting themselves and ensure they maximise the referral pathways to other services supporting prehabilitation to patients in acute and community services.

4. Personalised care - As part of the NHS long term plan, we need to continue to deliver personalised, tailored support based around what matters to patients. The aim is to continue for patients to have personalised prehabilitation care plans and the implementation of this can be achieved through the use of Holistic Needs Assessments, in ensuring the personalised care plans created include aspects of prehabilitation too. In supporting the delivery of universal prehabilitation with staff will enable robust, first line support and advice and will lead to comprehensive, holistic assessments and plans.

The use of the Patient Activation Measure will continue to be used with patients being seen to tailor prehabilitation interventions and plans. The PAM has the potential to provide wider information about cancer patients accessing acute services. It can also be used to determine support required for patients and be used to influence service development and improvement. Together with the Lead Cancer Nurse, it is being proposed to trial the use of the PAM with a wider cohort of patients accessing cancer services to determine; the activation levels across tumour sites and local demographics. It is intended patients will be assessed at a particular point in their cancer pathway, over a period of a few months, to give a snapshot of data. This will provide greater knowledge of who is accessing our services, inform the development and improvement of services in order to reach more patients and tailor the focus for those with lower levels of activation.

5. Virtual support – Whilst most patients access he hospital and meet their health care professionals regularly for appointments and support, some patients don't and if offered, may choose to seek support digitally, remotely and independently. The aim going forward is to develop the prehabilitation offer virtually, to broaden the offer and support to more patients, across wider demographics. This will include the offer of assessments over the telephone, virtually and potentially through the use of a digital application so assessments can be completed online. The prehabilitation lead distributed a survey to First Steps attendees to canvas the opinions about having information digitally. It is felt there is opportunity to develop this further.
6. Promotion – Many clinical areas and specialities are aware of programmes such as 'Enhanced Recovery after Surgery' however within cancer care this isn't widely acknowledged. The prehabilitation lead has written several case studies and blogs for the trust, Macmillan and NHSE and feels promotion of prehabilitation and the current project are still required to raise awareness of this to the wider team's and stakeholders.
7. Fitness tracker – Supporting people increase physical activity levels can be difficult if they are doing a home-based exercise programme. Understanding that not just increasing the time they are active but also the level of intensity can be difficult without one to one support. The use of fitness trackers can provide the patient with the ability to measure; time of activity, distance (walking, running, cycling, swimming) and heart rate. Providing a BORG scale (rate of perceived exertion) can help someone identify the level of exertion they need to exercise at that increases their heart rate and respiratory and cardiac function. However, this can be subjective. The use of a fitness tracker to measure heart rate can offer an objective marker of how much to exert ones-self within assessed parameters. The prehabilitation lead with support from the lung cancer specialist nurse are keen to trial the use of fitness trackers with lung cancer patients to determine if using them to set goals and monitor activity intensity offer another physical activity intervention for those patients who require more support being active, perhaps wont access community and council resources or leisure facilities and those with other comorbidities that place them at higher risk if exercising unsupervised by using a heart rate monitor as a guide.
8. Quality of life measure – It has been difficult to establish a validated and user-friendly quality of life tool. Advice was gained from Prehabilitation network groups, but this was a similar theme. The Prehabilitation lead initially began to use the EORTC – QLQ -C30, however this was lengthy and required support to analyse the results. Quality of

life is being introduced and measured within the Macmillan Holistic Needs Assessment however has not yet been incorporated. It is the intention to apply for the license to use the EuroQol EQ-5D-5L as this is shorter, easier to administer, user friendly with software to measure and analyse data.

## Section 15 References

Faithfull S, Turner L, Poole K, et al. (2019) Prehabilitation for adults diagnosed with cancer: A systematic review of long-term physical function, nutrition and patient-reported outcomes. Eur J Cancer Care.

Silver JK, Baima J. Cancer prehabilitation: An opportunity to decrease treatment-related morbidity, increase cancer treatment options, and improve physical and psychological health outcomes. Am J Phys Med Rehabil. 2013;92:715–27

https://calderdale.gov.uk/v2/residents/health-and-social-care/joint-strategic-needs-assessment/health/cancer#local-picture

https://www.england.nhs.uk/wp-content/uploads/2019/02/comprehensive-model-of-personalised-care.pdf

https://www.kirklees.gov.uk/beta/public-health-partners/jsna/pdf/KirkleesJSNAReport2010_9_Smoking.pdf

West Yorkshire & Harrogate Cancer Alliance Tobacco Control programme

# Section 16 Appendix

## First Step Cancer Programme - Responses

1. I understand what I can do to help myself live better with and beyond cancer

More Details

| | |
|---|---|
| Strongly Disagree | 0 |
| Disagree | 5 |
| Unsure | 13 |
| Agree | 13 |
| Strongly Agree | 7 |

2. I know about the information and support which is available to me

More Details

| | |
|---|---|
| Strongly Disagree | 2 |
| Disagree | 5 |
| Unsure | 12 |
| Agree | 13 |
| Strongly Agree | 6 |

3. I feel able to talk to my family and friends about my feelings

More Details

| | |
|---|---|
| Strongly Disagree | 2 |
| Disagree | 2 |
| Unsure | 4 |
| Agree | 14 |
| Strongly Agree | 16 |

4. I feel confident about making future decisions related to my life

More Details

| | |
|---|---|
| Strongly Disagree | 2 |
| Disagree | 1 |
| Unsure | 10 |
| Agree | 18 |
| Strongly Agree | 7 |

5. I am reassured about how I feel about myself

More Details

| | |
|---|---|
| Strongly Disagree | 2 |
| Disagree | 2 |
| Unsure | 18 |
| Agree | 9 |
| Strongly Agree | 7 |

6. I understand what I can do to help myself live better with and beyond cancer

More Details

| | |
|---|---|
| Strongly Disagree | 1 |
| Disagree | 0 |
| Unsure | 2 |
| Agree | 15 |
| Strongly Agree | 17 |

7. I know about the information and support which is available to me

More Details

| | |
|---|---|
| Strongly Disagree | 1 |
| Disagree | 0 |
| Unsure | 1 |
| Agree | 15 |
| Strongly Agree | 18 |

8. I feel able to talk to my family and friends about my feelings

More Details

| | |
|---|---|
| Strongly Disagree | 1 |
| Disagree | 2 |
| Unsure | 3 |
| Agree | 14 |
| Strongly Agree | 15 |

9. I feel confident about making future decisions related to my life

More Details

| | |
|---|---|
| Strongly Disagree | 2 |
| Disagree | 2 |
| Unsure | 5 |
| Agree | 14 |
| Strongly Agree | 12 |

10. I am reassured about how I feel about myself

More Details

| | |
|---|---|
| Strongly Disagree | 3 |
| Disagree | 1 |
| Unsure | 1 |
| Agree | 16 |
| Strongly Agree | 14 |

11. Which part/s of the session did you find most valuable/most enjoyable?

More Details

29
Responses

Latest Responses
*"Finding contacts, promoting exercise."*

12. Which part/s of the session did you find least valuable/least enjoyable?

More Details

24
Responses

Latest Responses
*"Financial benefits, Emotions."*

13. Is there anything you would like to see changed or included in future events?

More Details

25
Responses

Latest Responses

14. Did the session meet your needs at this point in your cancer journey? YES/ NO

More Details

33
Responses

Latest Responses

15. Do you have any other comments?

More Details

18

Responses

Latest Responses

16. Overall, I would rate this programme as.....

More Details

| | |
|---|---|
| Excellent | 27 |
| Good | 7 |
| Average | 0 |
| Poor | 0 |
| Very Poor | 0 |

17. I would rate this venue as...

More Details

| | |
|---|---|
| Excellent | 15 |
| Good | 15 |
| Average | 4 |
| Poor | 0 |
| Very poor | 0 |

## First Steps Survey Monkey responses

1. Following the session, have you read through the information provided in your pack?

More Details

| | |
|---|---|
| Yes | 5 |
| No | 0 |

2. Following the session, have you increased your level of physical activity? If YES, what are you doing now and how often? If NO, please explain why...

More Details

5
Responses

Latest Responses

*"No I have just continued with what I did before. Eg gym and swimmi..."*

*"No"*

*"No I have maintained the level I had before"*

3. Following the session, have you made changes to your diet? If YES please explain what changes you have made. If NO please explain why...

More Details

5
Responses

Latest Responses

*"No I enjoyed the diet I had and felt it fulfilled my needs"*

*"Yes just being mindful of what I eat"*

*"Yes ate less a bit more careful with caffeine and alcohol especially po..."*

4. Following the session, are you managing your emotions and sleep? Please explain further.

More Details

5
Responses

Latest Responses

*"Yes I have been on a couple of therapy courses while on radiotherap..."*

*"No"*

*"No there are things that I had control of and now don't eg continence"*

5. If appropriate, have you contacted local stop smoking services?

More Details

| | |
|---|---|
| Yes | 1 |
| No | 2 |

6. Do you feel you would benefit from further support or guidance with any of the above? Please provide a contact number if you would like a member of the team to contact you.

More Details

| | |
|---|---|
| Yes | 0 |
| No | 4 |
| Other | 1 |

7. Have you visited the Macmillan information service or attended a Macmillan coffee morning / support group or any other service offered? If Yes please state which.

More Details

5
Responses

Latest Responses

*"Yes the information service at the Bexley centre while undergoing my..."*

*"No"*

*"No"*

8. Do you feel the First Steps session has benefited you in the long term?

More Details

| | |
|---|---|
| Yes | 5 |
| No | 0 |

9. On reflection, which part of the session remains most memorable to you and that you still think about / consider?

More Details

4
Responses

Latest Responses

*"The positivity of the leaders of the session"*

*"All helpful in different ways. Patient experience talking "*

10. Any further comments regarding the session, what you have done since, or how you feel the session could be improved?

More Details

2
Responses

Latest Responses

*"I have since spoken with another cancer survivor "*

*"I think more preparation for the loss of control over time. Losing cont..."*

## Personalised Prehabilitation Care Plan

| | | |
|---|---|---|
| Name: | | DoB: |
| Date: | | |
| Personalised Care Summary: | | |
| Assessment results: | 1st Assessment | Re-Assessment |
| PAM Level: | | |
| QOL: | | |
| PG-SGA: | | |
| Weight: | | |
| Height: | | |
| BMI: | | |
| GAD-7: | | |
| PHQ-9: | | |
| IPAQ: | | |
| ISWT: | | |
| Sit to stand or grip strength: | | |

Treatment / Intervention plan (including details of onward referrals):

| |
|---|
| Physical Activity: |
| Nutrition & Diet: |
| Emotional wellbeing: |
| Smoking cessation / Alcohol reduction support (if applicable): |

Care plan completed by:

Review date:

Telephone review: Yes / No Clinic review: Yes / No