

# Macmillan Next Steps Cancer Rehabilitation – Mixed Methods Evaluation

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OF GLOUCESTERSHIRE, 2018.

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## Funding Declaration

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## Citation

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## Executive Summary

### Introduction

Macmillan Next Steps Cancer Rehabilitation (MNSCR: the “intervention”) is a bespoke NHS prototype that offers one-to-one, group support, and patient education (the “programmes”) to patients living within and beyond cancer in Gloucestershire. The aim of the MNSCR scheme is to support and empower individuals living within and beyond cancer to recover and take an active role in their care to improve their health outcomes and experience. The scheme also incorporates educational programmes targeted at colleagues working within the health and social care professions to provide a holistic, system-wide integration of care and support, and group support to people in a caring or supportive role to people affected by cancer. Participants are recruited by clinical referral, but may also enter the intervention through self-referral or referral from other social or volunteer services. The inclusion criteria for referral include being diagnosed with breast, prostate, or colorectal cancer; and living in Gloucestershire, or being registered with a GP within Gloucestershire. Patients are eligible for referral if they are pre- or post-treatment, have localised or advanced disease, but not if they are under the active care of palliative care.

This report provides a summary of the evaluation undertaken by the University of Gloucestershire during 2018 on the patient support aspects of the intervention.

### Objectives

The evaluation investigated the following objectives:

1. To investigate the effect of the intervention and its individual programmes (where sufficient data are available) on patient activation, using a validated measure (PAM), pre- and post-intervention.
2. To investigate the effect of the relevant programmes within the intervention that capture data on clinical outcomes pre- and post-intervention, with 12-week post-completion where available.
3. Investigate the nature of the referrals (i.e. sex, referral reason, place of residence, etc.) and their progress through the intervention and its available programmes.
4. To qualitatively explore the impact of the intervention within this patient group by using patient experiences and perceptions provided on self-complete feedback questionnaires.

### Method

Participants are referred via a referral form, by telephone, or by email. Pre- and post-intervention data are collected, including the Patient Activation Measure (PAM), the 13-item Functional Assessment of Chronic Illness Therapy Fatigue scale (FACIT-F), and clinical anthropometric measures. Participants are also requested to complete free-text feedback forms relating to each programme within the intervention.

### Results

Findings from this mixed-methods evaluation are summarised below:

- Patient activation increased overall by an average of 19.2%; with the majority showing increases in score ( $N=42$ , 66.7%) and level ( $N=34$ , 53.1%). In those that increased, the majority did so by one level ( $N=23$ , 67.6%), but larger increases were also seen.

- Statistically significant increases in patient activation level and overall score; significant decreases in fatigue, and significant positive changes in physical activity capacity, strength, and body composition.
- Participants reported an overwhelming appreciation for the intervention, its composite programmes, and the staff involved in delivering the sessions. MNSCR was viewed as an important and valuable service for those living within and beyond cancer.
- MNSCR provided the opportunity for patients to re-engage with themselves, and feel like they could move forward with their lives once more.
- Participants could quantify tangible changes to their physical and mental health, as well as show understanding of the importance for behavioural change in managing their long-term health.
- The programmes within the intervention provided a community for participants to engage with, informational and emotional support, and a confidence-inspiring environment created by staff.
- Difficulties in providing a universally relevant and informative curriculum appeared to be of concern to some participants. There is an indication that one way of improving this aspect would be to cluster groups of participants by treatment stage, but this requires some consideration in the future.

## Conclusions

These findings support the utility and value of the programmes offered by MNSCR, and the intervention as a whole. It is an ambitious intervention that has set out to provide comprehensive and inclusive sources of support, information, and learning for patients. To this end the initial findings appear that the intervention has been successful in improving the lives of those individuals that have been able to participate both objectively in key clinical outcomes, and subjectively through the words of the patients themselves.

## Recommendations

1. Based on the universality of benefit across patient sex, age, tumour group, and deprivation level, continue to offer the intervention to patients, but consider broadening to other tumour groups that might also benefit. Considering how to make the intervention more accessible to men might be advantageous to widen participation.
2. Continue to collect further data to support a more substantial quantitative evaluation.
3. Consider the collection of other clinically meaningful data that will allow detailed understanding of salient outcomes in this population (e.g. metrics of depression, anxiety, health-related quality of life, or wellbeing).
4. Participants have voiced recommendations to offer more sessions, and to offer participation earlier on in the treatment pathway.
5. Participants identified the potential for grouping cohorts based on stage of illness and treatment. This may ameliorate some of the identified challenges in engaged participation.
6. Ensure that programmes initiate with more specific information regarding content, and that expectations on involvement, intentions, and projected outcomes are clear.
7. Consider how the intervention might be made a formal part of cancer care for all, potentially at earlier stages of treatment pathway.
8. A mechanism for standardising the collection and coding of patient data (demographic, clinical, and personal) would be beneficial to the establishment of a robust and rigorous evaluation. This would enable a solid foundation of evidence to support further commissioning decisions, and provide important insight into what is clearly an ambitious and pioneering intervention.

## Lay Executive Summary

### What is the report about?

Macmillan Next Steps Cancer Rehabilitation (MNSCR: the “intervention”) is a bespoke scheme that offers one-to-one, group support, and patient education (the “programmes”) to patients living within and beyond cancer in Gloucestershire. It is a service offered by Gloucestershire Care Services NHS Trust that aims to improve recovery, health and wellbeing in patients with breast, colorectal, or prostate cancer by empowering them to take an active role in their care. The inclusion criteria for referral include being diagnosed with breast, prostate, or colorectal cancer; and living in Gloucestershire, or being registered with a GP within Gloucestershire. Patients are eligible for referral if they are pre- or post-treatment, but not if they are receiving care from palliative care.

This report provides a summary of the evaluation undertaken by the University of Gloucestershire during 2018.

### What did it aim to do?

The evaluation investigated the following objectives:

1. To investigate the effect of the intervention and its individual programmes (where sufficient data are available) on patient activation, using a validated measure (PAM), pre- and post-intervention.
2. To investigate the effect of the relevant programmes within the intervention that capture data on clinical outcomes pre- and post-intervention, with 12-week post-completion where available.
3. Investigate the nature of the referrals (i.e. sex, referral reason, place of residence, etc.) and their progress through the intervention and its available programmes.
4. To qualitatively explore the impact of the intervention within this patient group by using patient experiences and perceptions provided on self-complete feedback questionnaires.

### How did it do it?

Participants are referred via a referral form, by telephone, or by email. Pre- and post-intervention data are collected, including the Patient Activation Measure (PAM), the 13-item Functional Assessment of Chronic Illness Therapy Fatigue scale (FACIT-F), and clinical measures relating to strength and body composition. Participants are also requested to complete free-text feedback forms relating to each programme within the intervention.

### What did it find?

Findings from this mixed-methods evaluation are summarised below:

- People who take part in MNSCR increased in their ability to take ownership of, and to feel more in control of, their health.
- Taking part reduced the amount of fatigue that people felt, and helped them to increase their physical fitness.

- People who took part said that they felt MNSCR was an important and valuable service for those living within and beyond cancer.
- Those that took part also said that MNSCR provided them with the opportunity to re-engage with themselves, and feel like they could move forward with their lives once more.
- The people that took part said that they could identify changes to their physical and mental health, as well as understand of the importance for making lifestyle changes to manage their long-term health.
- People said that the programmes provided a community to engage with, important information, emotional support, and a confidence-inspiring environment created by staff
- People were concerned with providing activities and programmes that were relevant to all, which helped to identify that there might be ways of grouping people that take part in terms of where they are in their treatment journey.

### What happens now?

We have suggested some recommendations to the organisations that run MNSCR. These include:

1. No specific groups appeared to have benefited more (or less) than others, suggesting that the intervention is useful for all. Consider broadening access, and how the intervention can be made a formal part of cancer care for everyone.
2. To offer more sessions, and to offer participation earlier on in the treatment pathway.
3. Participants identified the potential for grouping cohorts based on stage of illness and treatment. This may ameliorate some of the identified challenges in engaged participation.
4. Ensure that programme content includes more specific information and that expectations on involvement, intentions, and projected outcomes are clear.
5. Consider how MNSCR might become a routine part of cancer care for all, and how it might be integrated into the treatment plan earlier on.



## Infographic

# Macmillan Next Steps Cancer Rehabilitation



## Introduction

MNSCR (the "intervention") is a bespoke scheme that offers one-to-one, group support, and patient education (the "programmes") to patients living within and beyond cancer in Gloucestershire. The scheme also incorporates group support for carers, and educational programmes targeted at colleagues working within the health and social care professions to provide a holistic, system-wide integration of care and support. Participants are recruited by clinical referral but may also enter the intervention through self-referral or referral from other social or volunteer services. The inclusion criteria for referral include being diagnosed with breast, prostate, or colorectal cancer; and living in Gloucestershire, or being registered with a GP within Gloucestershire. Patients are eligible for referral if they are pre- or post- hospital-based treatment, but not if they are actively under the care of palliative care.

The UoG were commissioned to undertake this initial evaluation of the MNSCR intervention, and this report presents findings from analyses of data collected since the intervention began in 2016.

## Evaluation Framework

The evaluation framework adopts a mixed methods design, utilising quantitative and qualitative data gathered by GCS during the undertaking of the intervention. The evaluation framework was designed to provide insight into process and outcomes of the composite programmes, as well as the intervention as a whole.

### *Aim of the evaluation*

To undertake a mixed methods process and outcome evaluation of the MNSCR intervention. The evaluation aimed to understand whether patients participating in the intervention gained any specific benefits (either clinical or subjective) from taking part in individual programmes, or the intervention as a whole. The data from this evaluation will provide an evidence base for the first time in this comprehensive and holistic intervention.

The evaluation included the following objectives:

1. Investigate the nature of the referrals (i.e. sex, referral reason, place of residence, etc.).
2. To investigate the effect of the intervention and its individual programmes (where sufficient data are available) on patient activation, using a validated measure (PAM), pre- and post-intervention.
3. To investigate the effect of the relevant programmes within the intervention that capture data on clinical outcomes pre- and post-intervention, with 12-week post-completion where available.
4. To qualitatively explore the impact of the intervention within this patient group by using patient experiences and perceptions provided on self-complete feedback questionnaires.

## Ethical considerations

The evaluation received ethical approval in September 2018 from the Gloucestershire Research Support Service (R&D reference: 18/006/CCGSE).

## Method

### Process of referral and data collection

Participants are referred into the intervention via a referral form, or by telephone or email. On arrival into the service they are discussed within the weekly multidisciplinary team (MDT) meeting to allow triage to the most appropriate programme depending on their needs. The patient is then accepted into the service and contacted. If booked onto one of the interventions is sent an appointment bundle which includes the Patient Activation Measure (PAM: 1). Depending on the programme, the patient is booked into they may also complete, or have taken: a bespoke health questionnaire identifying any issues that require more specialised support, forms for capturing anthropometrics (e.g. blood pressure), the 13-item Functional Assessment of Chronic Illness Therapy Fatigue scale (FACIT-F: 2), and a bespoke questionnaire regarding health behaviour. Demographic data were collected at referral, and patient engagement is assessed through a register of attendance. On completion of the programmes within the intervention the participants are asked to complete a free-text feedback form, the PAM and FACIT-F, as well as having clinical outcomes (e.g. sit-to-stand, grip strength etc.) measured once more, and have their anthropometric measures taken. A repeat for these measures is then also made 12 weeks post-completion in some cases. The data were anonymised and collated for University of Gloucestershire (UoG) evaluation by MNSCR.

### Quantitative data

Data collected by the MNSCR team were entered anonymously. Analysis for change pre and post the intervention was undertaken. Data collected included the following:

- Sex
- Age group
- Tumour site
- Post code
- Patient Activation Measure
- Session information (including programme attended, and level of attendance)
- Anthropometric and clinical outcomes data (i.e. heart rate, blood pressure, waist circumference, grip strength, sit-to-stand, three-minute step test, weight).
- Functional Assessment of Chronic Illness Therapy-Fatigue 13-item scale

### Qualitative data

Qualitative data comprised of the patient's experiences and perceptions of the programme, collected via a self-complete feedback questionnaire. Participants were asked to respond to the following statements and questions:

1. *"please describe the areas of the course that you found most valuable"*
2. *"please describe the areas of the course that you found least valuable or could be developed further"*
3. *"how do you intend to apply what you learnt on the course? What will you do differently? What do you think will be the effect of this?"*
4. *"what recommendations would you like to make for future courses?"*
5. *"if you have any views on how we could improve this support in the future, please provide comments here"*
6. *"please write any additional comments here"*
7. *"how would you describe cancer rehabilitation to others?" (Friends and Family only)*

The number and availability of data ranged for each of the programmes within the intervention. Data available for qualitative analysis were as follows:

- Take Control ( $N=145$ )
- HOPE ( $N=18$ )
- Healthy on Hormones ( $N=13$ )
- Recipe for Health ( $N=40$ )
- Time and Space ( $N=2$ )
- Friends and Family tests ( $N=42$ )
- Active Everyday ( $N=19$ )

Responses ranged from a few words, to small paragraphs of text. Data was uploaded to NVivo 11 which was used to store and manage the analytical process.

## Data analysis

### Quantitative analysis

Where available, comparisons between pre- and post-scores for scales, and any clinical data, were carried out using paired samples  $t$  tests or Wilcoxon signed rank test, depending on level of data. Comparisons between groups were carried out using Pearson  $X^2$  analysis or one-way ANOVA depending on type of data used. An alpha level of  $\alpha=.05$  was set to determine cut off for statistical significance. Any analyses with sample sizes lower than 30 should be interpreted with caution, and it is recommended that further data are gathered to add to these analyses to provide more robust evidence.

### Qualitative analysis

The qualitative data was analysed using inductive thematic analysis techniques (3). These included the following phases:

1. Familiarisation with the data - transcripts were read and re-read, with brief notes recorded to create preliminary ideas for the next phase of the analysis.
2. Codes of interest were generated by extracting and collating pertinent excerpts of the data.
3. Emerging codes were organised into broad themes that reflected the content and meaning of the data, and reflected the evaluation aims and objectives.
4. Themes were reviewed and refined in relation to the generated codes and the entire data set.
5. Themes were labelled and defined, attempting to capture the essence of the data it contained.

Thematic analysis was undertaken for each programme independently. Subsequently a comparison between the programmes was conducted to provide an overview of the intervention as a whole.

## Findings

### Quantitative findings

The quantitative findings addressed objectives 1-3:

1. Investigate the nature of the referrals (i.e. sex, referral reason, place of residence, etc.).

2. To investigate the effect of the intervention and its individual programmes (where sufficient data are available) on patient activation, using a validated measure (PAM), pre- and post-intervention.
3. To investigate the effect of the relevant programmes within the intervention that capture data on clinical outcomes pre- and post-intervention, with 12-week post-completion where available.

The findings are separated by specific outcome and/or programme where available.

### *The Participants*

Data exists for a total of 675 participants that have been referred to the MNSCR programme, and their summary data are presented in Table 1. The majority of referred patients were female ( $N=441$ , 65.6%), were referred after a diagnosis of breast cancer ( $N=321$ , 47.6%), and were from the lowest quintile of deprivation ( $N=119$ , 36.2%). A reasonably even distribution of age ranges was observed, with the marginal majority being within the 65-74-year-old bracket ( $N=195$ , 28.9%). No significant differences were observed in terms of deprivation by age group, sex, or tumour type, suggesting no over- or under-representations of deprivation in any of these categories.

Table 1. Demographic breakdown of all patients referred to MNSCR

Variable		Number	%
Age group	25-34	10	1.5
	35-44	40	5.9
	45-54	136	20.1
	55-64	149	22.1
	65-74	195	28.9
	75-84	116	17.2
	85+	29	4.3
Sex	Female	441	65.6
	Male	231	34.4
Tumour type	Breast	321	47.6
	Colorectal	195	28.9
	Prostate	155	23.0
Index of Multiple Deprivation Quintile	Highest deprivation	19	5.8
	High	21	6.4
	Medium	81	24.6
	Low	89	27.1
	Lowest	119	36.2

### *Patient Activation*

Patient activation comprises four distinct components: 1) believing that taking an active role in personal health is important; 2) being sufficiently confident and knowledgeable to act; 3) taking action to improve health; and 4) continuing that action even during times of adversity (1). The Patient Activation Measure (PAM: 1) was developed to measure this understanding of health-related self-efficacy, and has been used to understand differences between patients in clinical outcomes, as well as determine potential economic costs for patient care (4-6). Pre- and post-PAM data were available for 64 patients that have been referred to the programme. This smaller group comprised mostly of women ( $N=45$ , 70.3%), and were evenly split between breast ( $N=29$ , 45.3%) and colorectal ( $N=29$ , 45.3%) tumour types, with a minority having a prostate cancer diagnosis ( $N=6$ , 9.4%). Participants were mostly from the lowest two quintiles of deprivation ( $N=20$ , 31.3% per quintile), and were more commonly in the 65-74-year-old age group ( $N=19$ , 29.7%). There were no

significant differences at baseline or post-intervention in PAM level based on tumour type, patient sex, age, or deprivation level.

At baseline, the majority of participants were PAM level two ( $N=21$ , 32.8%) or lower. Post-intervention, the majority were at PAM level three ( $N=24$ , 37.5%) or higher. Table 2 shows a demographic breakdown of the participants that were able to provide pre- and post-intervention PAM data.

Table 2. Demographic breakdown of participants with pre- and post-intervention PAM data

Variable		Number	%
Age group	25-34	1	1.6
	35-44	4	6.3
	45-54	14	21.9
	55-64	17	26.6
	65-74	19	29.7
	75-84	9	14.1
Sex	Female	45	70.3
	Male	19	29.7
Tumour type	Breast	29	45.3
	Colorectal	29	45.3
	Prostate	6	9.4
Index of Multiple Deprivation Quintile	Highest deprivation	6	9.4
	High	2	3.1
	Medium	16	25.0
	Low	20	31.3
	Lowest	20	31.3
PAM Level	One	18	28.1
	Two	16	25.0
	Three	21	32.8
	Four	9	14.1

In this cohort, a significant increase in PAM overall score was observed after participation ( $56.1 \pm 11.86$  versus  $65.6 \pm 13.81$ ,  $t=-6.22$ ,  $df=63$ ,  $p<.001$ ), as well as PAM level ( $2.3 \pm 1.04$  versus  $2.9 \pm 0.98$ ,  $t=-5.55$ ,  $df=63$ ,  $p<.001$ ). The majority of participants increased in both overall score ( $N=42$ , 66.7%), and PAM level ( $N=34$ , 53.1%). Overall, a 19.2% increase in PAM score was observed across the sample. Table 3 shows the breakdown of PAM change in terms of overall score and activation level.

Table 3. Breakdown of PAM changes in score/level overall

	PAM Score (%)	PAM Level (%)
<b>Decrease</b>	9 (14.3)	4 (6.3)
<b>No change</b>	12 (19.0)	26 (40.6)
<b>Increase</b>	42 (66.7)	34 (53.1)

In those participants that increased in patient activation level ( $N=34$ , 53.1%), the majority increased by one level ( $N=23$ , 67.6%), nine increased by two levels (26.5%), and two increased by three levels (5.9%). Among those that experienced no change to their PAM level ( $N=26$ ), the majority were at level three ( $N=9$ , 34.6%) or 4 ( $N=8$ , 30.8%) indicating an already sufficiently high level of patient activation. Among the small number whose PAM level decreased ( $N=4$ ), there were two at level three (50%), and one each at levels two and four (25% each). Critically, the majority of each

activation group saw increases in their level, with no specific groups overly affected by decrease. A breakdown of level changes by baseline PAM level is presented in Table 4.

Table 4. Breakdown of PAM level changes by baseline PAM level.

PAM Level	Change	Number	%
PAM 1	Decrease	-	-
	No change	5	27.8
	Increase	13	72.2
PAM 2	Decrease	1	6.3
	No change	4	25.0
	Increase	11	68.8
PAM 3	Decrease	2	9.5
	No change	9	42.9
	Increase	10	47.6
PAM 4	Decrease	1	11.1
	No change	8	88.9
	Increase	-	-

In those patients whose overall score in patient activation increased ( $N=42$ , 66.7%), the majority began at level three ( $N=15$ , 35.7%), although similar representation was seen at levels one and two also, with a small minority at level four ( $N=2$ , 4.8%). Among those whose PAM score did not change ( $N=12$ , 19%), at baseline these were spread across the activation levels but larger groups were levels one and four ( $N=4$ , 33.3% each). For those whose scores decreased ( $N=9$ ), their baseline levels were mostly in level two ( $N=3$ , 33.3%), with the other levels seeing even representation ( $N=2$ , 22.2%).

### Specific patient activation elements

The PAM is comprised of several distinct patient activation concepts, and as such is interesting to examine by question. Comparing the pre- and post-scores for each of the questions, some significant and clinically meaningful differences emerge. Questions pertaining to medications, healthcare communication, and behaviour change all saw significant increases as a result of participating in MNSCR activities. Table 3 outlines the questions and their significant changes.

Table 5. Significant differences for aspects of patient activation.

"I know what each of my prescribed medications do."	2.9±0.57 vs. 3.5±0.61, $t=-4.93$ , $df=53$ , $p<.001$
"I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself."	3.1±0.70 vs. 3.5±0.59, $t=-2.62$ , $df=60$ , $p=.011$
"I am confident that I can tell a doctor or nurse concerns I have even when he or she does not ask."	3.3±0.68 vs. 3.6±0.60, $t=-2.46$ , $df=61$ , $p=.017$
"I have been able to maintain lifestyle changes, like healthy eating or exercising."	2.7±0.69 vs. 3.2±0.71, $t=-3.68$ , $df=61$ , $p=.001$
"I am confident that I can maintain lifestyle changes, like healthy eating and exercising, even during times of stress."	2.7±0.62 vs. 3.1±0.67, $t=-3.11$ , $df=60$ , $p=.003$

### Group differences in PAM score and level change

To understand whether any specific groups differed in their changes in patient activation, comparisons were carried out for tumour type, sex, age, and deprivation level using one-way ANOVA and both PAM level and score change treated continuously. There were no significant

differences in PAM score or level change for any of these groups, suggesting that the intervention effects change equivocally for both sexes, each tumour type, across all age groups, and at all levels of deprivation. To provide additional robust analyses, PAM level and score change were treated categorically and comparisons with the same variables were carried out using Pearson  $\chi^2$  analysis. Here, there were also no significant differences across groups, suggesting again that there are no patient or demographic characteristics associated with PAM score or level outcome (in categories of “increase”, “no change”, and “decrease”).

### *Fatigue*

Fatigue is a clinically important variable in patients living within and beyond cancer (7), and is highly related to overall wellbeing in these patients (8) as well as longer-term metrics of wellbeing such as being able to return to work (9). Participants undergoing the Active Every Day (AED) and Recipe for Health (R4H) programmes as part of MNSCR were given the Functional Assessment of Chronic Illness Therapy-Fatigue 13-item scale (FACIT-F: 10) both pre- and post-programme.

### *Active Every Day*

A statistically significant decrease in fatigue was observed for those participating in the AED programme after three months ( $35.0 \pm 7.67$  versus  $39.8 \pm 7.04$ ,  $t = -3.16$ ,  $df = 14$ ,  $p = .007$ ), with an overall 15.8% reduction in fatigue seen. The sample for this test was very small ( $N = 15$ ), and so limited conclusions can be drawn from the test. However, results are encouraging as, despite the increased activity associated with this programme, there was a mean increase in 4.8 points on the FACIT-F scale overall for participants (higher scores indicate lower fatigue). Looking at specific items within the FACIT-F, those taking part in AED only showed significant improvements for the item “I am unable to do my usual activities”, which could be reflective of the gains in strength or increase in a feeling of fitness that might be experienced in such a programme.

### *Recipe for Health*

A decrease in fatigue was observed for those participating in the R4H programme after three months, and was significant ( $33.4 \pm 10.64$  versus  $40.7 \pm 11.29$ ,  $t = -4.43$ ,  $df = 24$ ,  $p < .001$ ). Overall, participants decreased in fatigue by 26.6%. A mean decrease in 7.3 points on the FACIT-F scale was observed, with some participants increasing by as many as 26 points on this maximum 52-point scale (where higher scores indicate lower fatigue). Whilst population norms for the FACIT-F scale vary depending on participant sex and age, scores of 40.1 for males and 38.9 for females are seen in general population samples (10). Given that mean scores for fatigue following both of these programmes are very close to these figures, this is an extremely encouraging sign. Conversely, for R4H, each question demonstrated significant improvements from pre- to post-programme aside from “I need to sleep during the day”, “I am too tired to eat”, and “I need help doing my usual activities” where no significant differences were observed.

### *Clinical Measures*

As part of the intervention, participants’ anthropometric and clinical measurements were taken at the beginning of each programme, at the end of the programme (at six weeks for AED, four weeks for R4H), and then at three-months follow-up. Not all participants have available data for analyses at each of the required time points, however analyses have been carried out to determine whether significant differences occur at pre- and post-programme, and then at pre-programme and three-month follow-up (“follow-up”).



## Active Every Day

Physical activity capacity appears to be increased as a result of engaging with this six-week programme, with significant differences observed in strength, by sit-to-stand repetitions (at post-programme and follow-up); as well as in cardiovascular capacity by step up repetitions (again at both comparison points). Waist circumference appears to be significantly reduced post-programme, but this contrast is not significant at follow-up. The sample size for these comparisons is dramatically reduced at the three-month follow-up period, however, and so this may account for the lack of significance despite an overall reduction in waist size seen in those whose data were captured. There were no significant differences in any of the cardiovascular metrics (systolic blood pressure, diastolic blood pressure, and heart rate), although the sample sizes for blood pressure pre- and post-programme were sufficient for a relatively robust analysis. Looking at the mean values, systolic blood pressure did reduce both at post-programme and follow-up, but diastolic blood pressure increased at both post-programme and follow-up. Heart rate only decreased at the follow-up three-month period, but this was not significant. The lack of significant changes in cardiovascular measures for such an intervention is difficult to explain without further information regarding how and when the measures were taken.

Missing datapoints has impacted on sample size for many of these comparisons, and so limited conclusions can be drawn from those that include samples lower than 30. Table 6 shows each comparison grouping, the number of participants' data available, and the inferential statistical test results.

Table 6. Comparison of clinical data change for Active Every Day

Variable	Comparison point	Sample size (N)	Test of difference
Sit-to-stand (repetitions)	Post-programme	34	<b>25.4±7.14 vs. 41.0±13.32, t=-6.86, df=33, p&lt;.001</b>
	Follow-up	16	<b>24.6±7.05 vs. 36.2±9.26, t=-5.71, df=15, p&lt;.001</b>
Step up (repetitions)	Post-programme	36	<b>80.3±19.77 vs. 105.5±19.75, t=-9.17, df=35, p&lt;.001</b>
	Follow-up	16	<b>81.9±21.88 vs. 113.8±24.12, t=-7.66, df=15, p&lt;.001</b>
Grip strength (left)	Post-programme	16	56.1±13.69 vs. 59.3±20.00, t=-1.02, df=15, p=.324
	Follow-up	7	55.5±13.05 vs. 59.3±14.68, t=-0.91, df=6, p=.396
Grip strength (right)	Post-programme	16	55.0±16.94 vs. 59.09±16.97, t=-2.12, df=15, p=.051
	Follow-up	7	55.4±15.01 vs. 61.1±16.16, t=-1.86, df=6, p=.113
Waist circumference (cm)	Post-programme	29	<b>100.2±12.34 vs. 97.6±12.2, t=3.13, df=28, p=.004</b>
	Follow-up	14	97.9±9.73 vs. 94.9±12.83, t=1.64, df=13, p=.126
Systolic blood pressure (mmHg)	Post-programme	27	139.6±17.98 vs. 139.3±21.26, t=7.19, df=26, p=.921
	Follow-up	13	144.57±20.67 vs. 136.7±19.56, t=1.37, df=13, p=.193
Diastolic blood pressure (mmHg)	Post-programme	27	82.9±13.86 vs. 84.6±11.76, t=-0.61, df=26, p=.544
	Follow-up	13	77.6±18.12 vs. 78.9±14.37, t=-0.27, df=13, p=.791
Heart rate	Post-programme	19	74.6±8.50 vs. 76.84±10.33, t=-1.23, df=18, p=.234
	Follow-up	11	72.9±8.94 vs. 71.6±8.71, t=0.67, df=10, p=.520

Significant differences highlighted in bold

## Recipe for Health

Gains in physical activity capacity were observed for participation in R4H also, with significant increases in sit-to-stand and step up. Strength was significantly increased as indexed by right hand grip strength, but only for the longer follow-up comparison. Significant reductions in waist circumference and weight were observed at both post-programme and follow-up junctures, with reasonably sized samples for each comparison to provide sufficient support for this programme reducing patient weight and central adiposity. There were no observed significant differences in any

of the cardiovascular measures for the intervention, with sufficient sample sizes to provide relatively robust analyses. Statistical significance aside, the pattern of change appears to be different for each metric as well; with increases in systolic blood pressure, but decreases in both diastolic blood pressure and heart rate. Given the lack of consistency in the observed patterns for both AED and R4H it is possible that differences in measurement protocol might provide an explanation. Table 7 shows each comparison grouping, the number of participants' data available, and the inferential statistical test results.

Table 7. Comparison of clinical data change for Recipe for Health

Variable	Comparison point	Sample size (N)	Test of difference
Sit-to-stand (repetitions)	Post-programme	21	<b>23.2±6.27 vs. 29.2±6.98, <math>t=-8.94</math>, <math>df=20</math>, <math>p&lt;.001</math></b>
	Follow-up	32	<b>21.5±4.72 vs. 36.0±10.24, <math>t=-7.41</math>, <math>df=31</math>, <math>p&lt;.001</math></b>
Step up (repetitions)	Post-programme	32	<b>70.1±12.32 vs. 91.0±21.7, <math>t=-6.81</math>, <math>df=31</math>, <math>p&lt;.001</math></b>
	Follow-up	20	<b>68.5±10.11 vs. 94.7±21.85, <math>t=-6.96</math>, <math>df=19</math>, <math>p&lt;.001</math></b>
Grip strength (left)	Post-programme	20	50.1±14.27 vs. 51.7±14.16, $t=-0.97$ , $df=19$ , $p=.345$
	Follow-up	16	55.2±13.45 vs. 57.3±15.5, $t=-1.54$ , $df=15$ , $p=.145$
Grip strength (right)	Post-programme	21	51.9±12.18 vs. 52.9±13.18, $t=-0.50$ , $df=20$ , $p=.622$
	Follow-up	17	<b>54.7±12.94 vs. 59.8±13.13, <math>t=-2.43</math>, <math>df=16</math>, <math>p=.027</math></b>
Waist circumference (cm)	Post-programme	41	<b>104.7±10.63 vs. 100.7±10.39, <math>t=5.80</math>, <math>df=40</math>, <math>p&lt;.001</math></b>
	Follow-up	25	<b>106.2±11.12 vs. 101.3±10.80, <math>t=5.66</math>, <math>df=24</math>, <math>p&lt;.001</math></b>
Weight (Kg)	Post-programme	46	<b>85.6±12.95 vs. 84.8±13.26, <math>t=3.79</math>, <math>df=45</math>, <math>p&lt;.001</math></b>
	Follow-up	28	<b>88.9±13.51 vs. 87.4±13.43, <math>t=2.89</math>, <math>df=27</math>, <math>p=.007</math></b>
Systolic blood pressure (mmHg)	Post-programme	46	139.9±23.32 vs. 140.3±16.99, $t=-0.16$ , $df=45$ , $p=.876$
	Follow-up	27	145.2±23.70 vs. 144.3±18.86, $t=0.27$ , $df=26$ , $p=.789$
Diastolic blood pressure (mmHg)	Post-programme	46	86.8±12.24 vs. 83.4±13.34, $t=1.77$ , $df=45$ , $p=.084$
	Follow-up	27	87.9±10.15 vs. 85.6±9.39, $t=1.15$ , $df=26$ , $p=.262$
Heart rate	Post-programme	45	75.6±11.83 vs. 75.8±12.91, $t=-0.08$ , $df=44$ , $p=.934$
	Follow-up	26	74.2±13.43 vs. 74.3±11.61, $t=-0.05$ , $df=25$ , $p=.962$

Significant differences **highlighted in bold**

### Attitudes, intentions, and behaviours in regard to weight loss

As part of the R4H programme, the MNSCR team provided participants with a questionnaire to assess their attitudes, intentions, and behaviours regarding maintaining a healthy weight, diet, and overall lifestyle. Aside from overall impact on general health and wellbeing, obesity is known to be a risk factor for both cancer incidence and recurrence (11-13). Therefore, promoting weight loss and positive behaviour change with regard to diet, exercise, and eating behaviours are ideal targets for supporting those living within and beyond a cancer diagnosis. Adherence to exercise and weight loss behaviour change programmes have been shown to effect an up to 60% reduction in cancer incidence (14), making them an important clinical adjuvant for the longer-term prevention of cancer pathologies. The R4H intervention is principally aimed at providing constructive informational support to encourage and facilitate weight management via diet and exercise. The questionnaire was administered pre- and post-programme (at four weeks), providing a direct perspective on how the intervention might have influenced change in attitude and knowledge regarding healthy lifestyle.

At baseline, participants rated the importance of losing weight relatively highly (mean 8.6/10), but control over weight and eating habits as quite low (mean 5.2/10, 6.8/10, respectively). Eating habits were reported to be relatively good, with the majority reporting more frequently to never skip meals (breakfast:  $N=34$ , 69.4%; lunch:  $N=33$ , 68.8%; dinner:  $N=41$ , 83.7%). Behaviours related to

food choice, however, appeared to be an important aspect for improvement. Reports of eating between meals (one to three times a week:  $N=25$ , 51%), and eating out or having takeaways (one to three times a week:  $N=39$ , 83.0%) were reasonably high; and frequency of eating fruit (one to two a day:  $N=30$ , 61.2%) and vegetables (one to two a day:  $N=28$ , 57.1%) more commonly in the lower ranks of reporting. Consumption of alcohol was most frequently reported to be never ( $N=18$ , 39.1%), or comparatively frequently (three to four times a week:  $N=12$ , 26.1%). Reports of weekly exercise were good, with the majority ( $N=15$ , 36.6%) reporting exercise at once or twice per week, but in shorter duration (30 minutes:  $N=14$ , 34.1%).

The sample sizes for each of the comparisons are very small, and so limited interpretation of the findings is possible. There do appear to be indications for positive behaviour change in terms of the amount of control individuals feel over their weight and their eating habits, and a significant reduction in eating unhealthy snacks, snacking between meals, and speed of eating. These results are encouraging, and looking at the changes between each measure they are moving in a more positive direction, even if the test does not attain statistical significance with this small sample. Further data are required to run robust analyses for these items.

Table 8. Comparisons of health behaviours before and after Recipe for Health

Question	Number	Test of difference
How important is losing weight to you at the moment (0-10)?	17	8.7±1.89 vs. 8.1±2.09, $t=1.21$ , $df=16$ , $p=.243$
How much control do you feel you have over your weight (0-10)?	17	<b>5.1±1.92 vs. 6.7±2.45, <math>t=-2.30</math>, <math>df=16</math>, <math>p=.036</math></b>
How much control do you feel you have over your eating habits (0-10)?	17	<b>6.7±2.26 vs. 7.9±1.35, <math>t=-2.42</math>, <math>df=16</math>, <math>p=.028</math></b>
During a normal week, how many times do you skip breakfast?	17	$Z=-1.41$ , $p=.157$
During a normal week, how many times do you skip lunch?	16	$Z=-1.41$ , $p=.157$
During a normal week, how many times do you skip an evening meal?	17	$Z=-0.27$ , $p=.785$
During a normal week, how many times do you choose an unhealthy snack?	17	<b><math>Z=-2.46</math>, <math>p=.014</math></b>
During a normal week, how many times do you buy a takeaway or go out to eat?	16	$Z=-0.97$ , $p=.330$
During a normal week, how many times do you eat in between meals?	17	<b><math>Z=-2.08</math>, <math>p=.038</math></b>
How many servings of fruit do you usually eat per day?	16	$Z=-1.41$ , $p=.159$
How many servings of vegetables do you usually eat per day?	16	$Z=-1.61$ , $p=.107$
How many servings of starchy foods do you eat per day?	15	$Z=-1.41$ , $p=.159$
What is your speed of eating?	15	<b><math>Z=-2.12</math>, <math>p=.034</math></b>
How often do you drink alcohol?	15	$Z=-0.88$ , $p=.380$
How many days a week do you currently exercise?	4	$Z=-1.34$ , $p=.180$
How many minutes in total over a week do you exercise?	0	Insufficient follow-up cases for analysis

Significant differences highlighted in bold

## Qualitative findings

The qualitative findings addressed objective 4:

4. To qualitatively investigate the impact of the intervention within this patient group by using patient experiences and perceptions provided on self-complete feedback questionnaires.

Findings that emerged from the qualitative analysis are presented in themes and sub-themes. Due to the limited number of participants it must be noted that these outcomes are not generalisable. Furthermore, the limited number, particularly when viewing the programmes independently, means that anonymity is difficult to maintain, so pseudonyms or reference numbers to quotations have not been included. Considering the limited capacity of this report the themes from all of the individual programmes have been summarised and will be discussed simultaneously; thus, the discussion is representative of the intervention as a whole (including limited reference to the colleague educational programme where appropriate). While it is noted that the colleague's voices are not relevant to the objectives of this evaluation *per se* their feedback provides valuable insight into best practice for education and learning within the health and social care field. Table 9 (p.32) provides an overview of the entirety of the themes and the related sub-themes that emerged for each of the programmes. Three themes emerged from the overall analysis, these along with their related sub-themes, are presented below:

1. Benefits
  - a. Changes to the self
  - b. Education and learning
  - c. Enhanced health
  - d. Intent for behavioural change
  - e. Social
  - f. Support from professionals
2. Challenges
  - a. The session
  - b. Current health and treatment journey
  - c. Time
  - d. Lack of self-confidence
3. Recommendations
  - a. Timing
  - b. Participants
  - c. Session content
  - d. Access

### Themes

#### Benefits

Benefits referred to the perceived positive changes to health, well-being and overall quality of life that attending the intervention encouraged the participants to make. Additionally, benefits referred to the factors that facilitated the patients' ability to implement such changes. Sub-themes included: Changes to the self, education and learning, enhanced health, intent for behavioural change, social, and support from professionals.

#### Changes to the self

##### *Self-confidence*

Patients perceived that attending the intervention provided them with a renewed sense of self-confidence that enabled them to move forward positively with their lives. The excerpts below

highlight how, with the support of the intervention, participants felt able to (re)engage in physical activity and exercise:

*I took a 2-year break from gym and Pilates due to my lack of confidence after having 2 serious leak problems after stoma operation which weakened my confidence. Going to a class where everyone has issues is a great way to quickly get back into to the swing of things and regain confidence.*

*I have gone back to Zumba...and Nordic walking with my son once a week. [The intervention] has shown me what my body can do post-surgery and given me the confidence to get back to exercising "normally" again.*

*When you finish treatment sometimes you are not ready to face things on your own. Joining the next steps programme gives you the confidence and support to take up exercise.*

Furthermore, the advice received as part of the intervention reassured patients not only of their capability to manage their health...

*I had an appointment with the dietitian because I felt I should explore every avenue to control my frequent bowel movements. She was helpful and made me decide that I was already doing all I can.*

...but also, of their ability to sustain, and build upon, any positive changes that the intervention had inspired:

*Active Everyday gave me the confidence to make exercise part of my life.*

*I feel stronger and better in myself now...I feel able to carry on and achieve my goals.*

*Great guideline regarding nutrition and exercise. I feel I can carry on by myself doing things right.*

### *Self-kindness*

By attending the intervention patients were offered a time and space in which they were able to self-reflect on their cancer journey. In doing so, the participants became aware of the importance of self-kindness for their health and well-being. The utterances below depict the patient's realisation of their need to be kinder to themselves as well intentions of how they plan to do so:

*[The intervention] has helped me recognise the importance of time for me.....!*

*I realise that I need to be my own best friend, so I will spend more time nurturing myself.*

*I do tend to have negative thoughts about myself, so I will try to not be so hard on myself and realise that no one is perfect.*

*[The intervention] gave me permission to look after myself a bit more. I learnt that it is OK to make time for me and to value myself.*

*I will put myself first, be more aware of how I am feeling and the impact it is having on my life.*

*[I will not] beat myself up. [This will] result in being healthier, cutting the odds of reoccurrence and being mentally more healthy.*

### *Sense of self*

The quotes below highlight how cancer diagnosis and treatment can make people lose sight of who they are. However, the quotes further infer that attending the intervention helped patients to regain their sense of identity which they feared had been lost as a consequence of their ill-health:

*You feel like you lose your identity during treatment, but the rehabilitation helps you to find yourself again.*

*[The intervention] is a tool kit which helps you put yourself back together. As the cancer journey just wears you down.*

*I feel happier and fitter. Back to my normal self.*

*This course gave me the knowledge, confidence and skills to become fit again. More importantly it made me feel like cancer hadn't changed or depleted me in any way. My positivity is almost back to normal.*

The above excerpts also suggest that by 'finding oneself' people have a renewed energy, feel happier, and are more positive and content to continue living their daily lives.

### *Education and learning*

The participants reported that the intervention increased their knowledge and understanding of health enhancing techniques and informed them of how such techniques could be incorporated into their daily lives:

*[The intervention] gave me more insight into how my thoughts can spiral down into a 'film' being played out in my mind and how I have the power to choose to break that cycle. I realise that I create my own suffering and that I can learn to control this. Very useful information provided that I can continue to look at.*

*The rehab service provided by staff has given me a solid start to progress further. I am military and feel I have benefitted so much and have been given exercises to keep working on into the future.*

*It was valuable to learn a coherent message about food quality, types etc. and to learn some exercise that I can build into my daily routine.*

Highlighted in the excerpts above, the patients believed that their increase in knowledge, as a result of attending the intervention, would enable them to take more of an active role in their care. Participants further recognised how the range of programmes and support available offered them a holistic cancer rehabilitation care package from which they benefitted considerably:

*I benefitted from the Take Control workshop and meeting [the] Personal Trainer, who was very helpful advising me on the exercises I could undertake safely and providing me with an on-going programme after the 6-week course. There are other courses on offer if required i.e. Dietitian, Physio. Definitely a worthwhile programme.*

*McMillians [sic] gave me physiotherapy, a personal trainer and Active Everyday Course. This gave me the knowledge, confidence and skills to become fit again.*

The quotes below identify just some of the topics that patients were able to understand more about from attending the intervention:

*Techniques to help exercise more*

*Improving my meditation technique*

*Mental aspects of hormone therapy and how hormones effect you*

*How diet and exercise can affect outcome*

*Dietary information and how to lead a fit and healthy lifestyle*

*What to eat, portion control, mindful coaching. How to set goals. Benefits of activity, how much to do, what exercises and how often. How to manage bad days and setbacks.*

*Learning how it feels to use my body well*

*Relaxation. Learning to be mindful and take time when pressure builds to stop and take stock. Learning to sit and do 'nothing'*

*Information on managing stress, sleeping and eating better, fatigue management, goal setting, communication, fear of recurrence, mindfulness, and priorities*

Furthermore, the patients stated how being provided with an information pack was useful. They illustrated how this provided them with information, guidance and advice that they were able to refer back to as and when they felt ready and able to do so:

*All the sections in the booklet were very valuable and enjoyable especially the breathing exercise. I will take the information pack and go through it in more detail. But some information from today has already been helpful.*

*I will refer to my workbook and share information with my husband and I will carry out the breathing exercises.*

### Enhanced health

Patients reported that their health had improved as a consequence of attending the intervention. Although physical and mental health enhancements are discussed independently below, it is important to recognise that, in most instances, these were described in unison; i.e. improvements to physical health also resulted in improvements to mental health and vice versa.

### Physical health

A number of the patients reported how, as a result of attending the intervention, they were able to make significant behavioural changes, such as joining an exercise class or eating more nutritionally, exemplified below:

*Exercise has become more integral to my lifestyle rather than as the occasional add on.*

*[Since attending the programme] I have been spending less time on the sofa and attending circuits and yoga, walking once a week and making an effort to go out.*

*I have breakfast, try not to snack, do not eat after 8pm, have upped my vegetable's and cut down on meat, cut out fizzy drinks, go to exercise classes and walk more [since attending the programme].*

*My husband and I have started swimming. We intended to go only once a week to begin with but have actually managed twice and sometimes 3 times and we are really enjoying it.*

*I try using the 3 out breath technique regularly. I have bought a Fitbit and can see my pulse rate drop! I am walking a lot more. I am trying a lot harder to put my health as a priority.*

These behavioural changes, in turn, were perceived to aid the participants physical health. One of the most predominant indicators of enhanced physical health, highlighted in the quotes below, was weight loss:

*I lost 3lb and my core muscles and abdominals are much stronger.*

*Having decided to take part [in the intervention] the results have been good. [I have] lost weight (13 stones) [sic] and reduced waist by 7cm.*

*I have lost 1 ½ stone and am feeling brighter.*

*Definitely less fatigued and I need to put more holes in my belt!*

Additionally, patients described how the intervention helped them to feel fitter, stronger and more resilient:

*I am fitter and facing obstacles with a confidence and not giving up. I will enrol in future exercise classes. No more couch potato!*

*Great support at a difficult time. [The intervention] has helped me regain fitness and reduced my risk of injury.*

*I have much more energy and want to be out and about. I am able to maintain activity for longer periods.*

*I have more energy, get less weary and can tackle more jobs more frequently. I think my sleep pattern is marginally better too.*

*I am able to work in the garden for a bit longer and can walk further.*

Patients continued to describe how the improvements made to their physical health facilitated their overall quality of life and well-being both in terms of symptom reduction ...

*[I am experiencing] less joint pain.*

*I had a 6-month check-up and I was advised by the CNS that she was impressed by the strength of [my] core and what they thought was a hernia initially was no longer there.*

*I have started Pilates and I am maintaining that, I am regularly walking and my use of pain killers has reduced.*

...And in terms of their improved ability to complete everyday tasks:

*I am able to tackle all the stairs at work now without being totally exhausted.*

*[I have benefitted from] using chairs without arms, using stairs [and not] lifts; easier movements.*

### *Mental health*

Attending the intervention helped to enhance patients' mental health and well-being in a number of ways. Firstly, by learning about and applying mindfulness techniques, the participants suggested that they were able to feel more relaxed and less stressed than they previously had been. This is highlighted in the excerpts below:



*I have had a very positive experience. Following the 'Take Control' session I had one to one mindfulness sessions which really helped with my stress and mental health. [I now] continue to practice mindfulness.*

*[Since attending the course] I am more able to cope with stress, I am in more in control [of my life] and I have a more positive mind-set...I am not so worried about silly things that don't really matter.*

*Since my mindfulness course I do take time to relax and reflect more often and step back when I am upset or stressed.*

*[Since the intervention] I continue to... be more positive and not dwell on negativity.*

Secondly, by attending the intervention, the patients reported that they learnt, and were able to apply, techniques to more efficiently manage and improve their sleep:

*[Mindfulness] has helped me get back to sleep when I have woken in the night and find myself over thinking everything. I have tried to concentrate on my breathing and empty my mind...*

*Trying to be grateful for something last thing at night [made me] sleep better and wake up with a positive (even humorous) thought - it works most of the time!*

*I do practice mindfulness when negative thoughts creep in.... I use it to help go back to sleep if awake in the early hours.*

Thirdly, the patients had a more positive outlook on life and were more enthusiastic about their future after attending the intervention. Participants reported feeling:

*More positive with life and willing to take chances and opportunities that I would not normally do.*

*Brighter [and] ready to take on more [in life].*

*More positive, looking forward to the future and enjoying each day for what it is.*

*Much less depressed and more positive about myself and the future.*

On the whole, the intervention was '*emotionally and psychologically helpful*'. It enabled the patients to '*feel happier and in more control*' of their lives.

#### Intent for behavioural change

Due to a number of factors, such as the limited duration of the programmes and the circumstances of the participants, a number of individuals reported that they had been unable to apply behavioural changes since attending the intervention. However, they remained enthusiastic about, and thus still planned to implement, some of the lifestyle changes that they had been introduced to at the course. Participants stated that they intend to:

*Look into using mindfulness.*

*Get a personal trainer [to achieve my] personal goal of running again and I will try to do mindfulness breathing - something that I would have pooh poohed before!*

*Keep snacking out of my life, reduce portion sizes and continue to walk daily. Target selective exercises into my daily routine.*

*Do more exercise...I will follow the lessons learnt [from the intervention]. I will tighten up my diet and exercise regime. I will concentrate on my physical fitness and make small changes to my diet. [I intend to] sign up for 1 to 1 training...I will attempt to reduce and improve my food intake and I have arranged to meet [the personal trainer] to discuss exercise.*

*Do some form of physical exercise everyday...try to eat my '5 a day' and hopefully lose some excess weight.*

*Investigate the gym and do more walking...do another Macmillan workshop for body image.*

Thus, as documented above, the intervention acted as a source of motivation that encouraged the participants to plan significant behavioural changes in an attempt to improve their overall quality of life.

### Social

The patients perceived one of the most predominant benefits of the intervention to be meeting other people who, they believed, were 'going through a similar journey' to themselves:

*This course is wonderful for the meeting of others going through the same journey.*

*I really appreciated talking with a group of people in similar situations.*

*It was great to meet with others who have been on a similar journey and exchange information and views.*

This offered the participants the opportunity to share experiences with, and acknowledge the struggles of, one another in a unique and sympathetic manner:

*For the first time since being diagnosed I felt comfortable in the company of people who have been on a similar journey to myself. All the emotions that were discussed in the meeting I could relate to.*

*I felt it beneficial going along to workshop, meeting other people and listening to their experiences and realising that others had felt exactly as I did on being told you had Breast Cancer.*

*It was nice to communicate with people in the same situation and [realise] that you are not alone in your problems and concerns.*

*I found this course excellent and motivational it was nice to be open and hear everyone else's experiences, it made me realise that I am not alone.*

Described in the quotes above, talking to 'like-minded people' helped to reassure individuals that they were not alone in their thoughts, feelings and emotional struggles. Furthermore, the excerpts below demonstrate how meeting people in a similar situation to themselves facilitated the patient's confidence to be able to move forward more positively with their lives:

*I'm constantly questioning the way I feel, which most of the time is negative and not conducive to my recovery or well-being. Being able to listen to other people's stories and concerns really helped me feel less anxious, worried and vulnerable, giving me that confidence boost I so desperately needed.*

*It has been great to meet people in my position and talk about various subjects around cancer openly whether it be physical and emotional problems and it has allowed me to move on more positively so it has been helpful emotionally as well as the health benefits.*

Finally, in terms of the social benefit, the quote below suggests that being around others in similar situations offered the individuals a sense of relief in which they were able to drop their fictitious pretence and be themselves:

*Now that I am disease free I feel I should be on top of the world but most of the time that is not how I feel. I now know others feel the same! What a relief, it's ok to feel the way we do. It is also ok to ask for help professional or from family and friends.*

### Support from professionals

The support that the patients received from the professionals was perceived to be highly beneficial and key to the successful running of the programmes, as suggested below:

*I found this morning's attendance very worthwhile the content was suitable for a wide variety...something for everyone...By its nature the success or failure of this sort of session must depend very much on the facilitators. My group were very lucky indeed to be guided by [brilliant facilitators], it was hard to imagine anyone doing it better.*

The facilitators were believed to support the patients in a number of ways including providing them with useful information and instructions, setting them achievable and motivational goals, being approachable and good listeners, and being knowledgeable, understanding, and encouraging. This is depicted in the excerpts below:

*The cancer dietitian and physio were able to answer my questions regarding changes to diet and treatment recovery. The physiotherapist provided useful instructions on massage of scar tissue and reassurance on progress. The personal trainer was brilliant at bench marking fitness and then providing achievable but challenging goals and monitoring progress. Fantastic service!*

*[The] team were very approachable - genuinely wanting to help even when work commitments made it difficult to join scheduled courses, alternatives were offered.*

*[The facilitators] have delivered the course excellently. They are encouraging and motivating they are sensitive to us as individuals and deliver a clear message.*

*The help and support I received was outstanding! The physiotherapist helped me with my hip as well as fatigue. [They] are wonderful!*

*[The professionals] were wonderful. Everything [was] explained brilliantly and very supportive. They made you feel that everything is achievable, and nothing was too much trouble.*

The quote below sums up one individual's experience of how the support that she received from both the delivering professionals, and from the service as a whole, impacted her health and well-being:

*Macmillan was there at just the right time to provide support and advise when my body and mind were so malfunctioning that I did not know what to do. The staff have immense experience and it was this confidence in them and what was offered which empowered me to*

*take control and heal. My sincere thanks and hope that you can continue to help others in a similar position.*

### Challenges

Challenges referred to the perceived limitations associated with the intervention and to the barriers that prevented the participants from experiencing positive outcomes as a result of attending the course. Sub-themes included: The session, current health and treatment journey, time, and lack of self-confidence.

### The session

A number of the participants suggested that they did not benefit from, or enjoy, the sessions as much as they could have because they found it difficult to hear. One patient describes his difficulties below:

*I was unable to hear quite a lot of what was said at the workshop. I am not severely deaf having had operations to both ears and don't usually struggle with ordinary conversations. However, I would imagine that a lot of my age group are deaf and would have similar problems. The lack of a loop system and loud noise from traffic exacerbated the problem.*

Furthermore, the participants highlighted that the emphasis of the information delivered on the programme was not always relevant to their current situation or circumstance:

*I found this morning's attendance very worthwhile [but] the content...could have done with less emphasis on nice things to eat\drink as I am very limited at the moment... Diet is not applicable to me in my current health position.*

*All parts [of the programme] were interesting although not all parts for me...sleep problems are not for me... I don't have a problem with sleep.*

Finally, it was recognised that the content of and atmosphere within the sessions, while trying to support individuals, could actually have the adverse effect:

*While offering advice on the emotional side of things... "ways to manage" could, in some cases, encourage self-pity, old fashioned perhaps but I think there should be more emphasis on self-reliance "a bit of back bone".<sup>1</sup>*

### Current health and treatment journey

Considering the inclusion criteria regarding time of referral (pre- or post- treatment) patients attending the same programme could, potentially, be at very different stages in their cancer and treatment journeys. Some individuals perceived this to have a detrimental influence of their experience of the intervention. Depicted in the quotes below patients express how feeling 'unlike' the majority of the group exacerbated their feelings of loneliness and anxiety:

*I felt as though I was in a different boat to everyone else around the table in terms that my prostate cancer had spread to my bones.*

*It appeared that everyone else were or [had been] going through radiotherapy which I had not.*

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<sup>1</sup> Take Control – "Please describe the area/s of the course that you found least valuable/least enjoyable and/or areas that could have been developed further.

*It felt very 'unsafe' as I hadn't built up sufficient trust as a group.*

Although the inclusion criteria stated that people receiving palliative care could not be referred to the programme, it appeared that one individual may have been receiving palliative care. It is possible that their cancer became more aggressive once they had already been referred to the intervention (however this cannot be concluded from the data). Reasons aside, this individual did infer that *'it was difficult being with others whose cancer was not palliative.'* This supports the intervention's referral criteria suggesting that inviting individuals into treatment with more healthy others may be detrimental for all involved.

#### Time

Firstly, *time* refers to the *time in their cancer journey* that the patients were referred to the intervention (i.e. pre- or post-treatment). Illustrated in the excerpts below, a number of individuals perceived that the timing of their referral was inappropriate or uncondusive to their cancer care.

*Within days of being advised of prostate cancer I received a letter stating I had been referred to [the intervention]. I have not started Radiotherapy yet and have had no adverse effects of the hormone therapy, so I have had no need for your dietitian/ personal trainer etc. etc. Surely support should be offered after treatment has commenced and not before then the services might be of benefit to patient.*

*I attended the Tak[e] Control workshop approx. 3 months after discharge from oncology clinic. My chemotherapy and radiotherapy sessions were completed approx. 1 year before (ongoing Herceptin injections meant I wasn't discharged from treatment until 9 months later) so a lot of the topics discussed in workshop had already been dealt with by myself.*

The other predominant concern with regards to *time* related to the patients perceived lack of time. They inferred having difficulties implementing and sustaining behavioural changes into their daily lives due to prior commitments, and thus, a lack of time to be able to do so:

*[I am] currently studying and not having time to improve my physical wellness.*

*I have been trying to eat more fruit, think about what I am eating and portion sizes [but] it is not always achievable as I am back at work and currently working 6 hours 5 days a week as well as helping my elderly father.*

*I think that work is a major challenge to fit all exercise in. I have managed [exercise] by doing housework and shopping [but] I have not eaten so well since returning to work.*

*I had intended after leaving the course to make changes in my practice and outside of work...this lasted around 24 hours!*

#### Lack of self-confidence

The patients admitted that they were still vulnerable to making the *'wrong'* choices with regards to their health and well-being. Depicted below, the participants reported that they found it difficult to *'confront doubts within themselves'* particularly when they were feeling low or fatigued:

*Fatigue sometimes means I have not chosen the healthy options. I have cooked something quickly and easy like frozen meals or oven chips and pizza.*

*I still enjoy biscuits. If [I am] feeling low or weak willed they creep back in.*

The patients further highlighted their lack of self-confidence to be able to implement and sustain positive behavioural changes in their daily lives:

*I have tried to be much more mindful to take time out and to be more self-aware but it is not easy to sustain.*

*I tried to meditate...I didn't manage it!*

*I have tried to make many changes but it is challenging to cut down on alcohol.*

*I [drink] less alcohol now although I still have the odd glass. I've not been eating less chocolate. I am a bit addicted to hot chocolate now.*

## Recommendations

The final theme *recommendations* referred to factors of the current programmes that the patients believed could be altered to enhance their overall experience of, and their perceived efficacy of, the intervention. Sub-themes included: Timing, participants, session content and access.

### Timing

The majority of participants perceived that that Next Steps cancer rehabilitation intervention was a '*valuable tool for people recovering from cancer*'. As such, they thought that the programme should be sustained. Individuals appreciated the potential that continuing the course could contribute to the lives other people that may be struggling with the effects of cancer in the future:

*[The programme was] inspirational. Please keep this course going so many, many more people can benefit.*

*Keep doing the courses, they are brilliant...a real life saver.*

*Continue doing what you're doing it's very worthwhile.*

Further, the patients were very keen for the duration of the intervention to be increased. Described below, patients thought that this would help to re-enforce the lessons learned from attending the programme:

*More and longer as it is inspirational.*

*The relaxation session could be longer. Again thoroughly enjoyable and not a negative.*

*Many new exercise techniques were demonstrated and taught however more sessions i.e. a longer course would be helpful to fully grasp and implement the techniques.*

The other predominant recommendation was that the intervention gets introduced to patients at an earlier stage in their cancer treatment:

*Try to engage people as soon as practicable after their clinical treatment has ended.*

*Personally speaking I would like to have had a course like this sooner in my recovery.*

*Try to provide info[rmation] at an earlier stage of treatment.*

## Participants

The patients recommended that the intervention should comprise of individuals that are at a similar stage of treatment to one another. This, they proposed, would enable the participants to share ideas of how to best manage the symptoms of their condition with others, of whom, they have a more comparable understanding with:

*I personally feel that I would have benefitted by being with other people with prostate cancer that had spread to the bone in order to understand how they are dealing with it and managing it in general.*

Additionally, patients proposed that their partners should be invited to attend the intervention to a) provide them with additional support, and b) to ensure their significant other has access to support for themselves:

*It would be useful to know that partners could attend... Maybe cover dealing with reactions [to having a partner be diagnosed with cancer] from family and friends and discuss how to help them too.*

Having small participant numbers was viewed favourably because this minimised the participants susceptibility to feeling overwhelmed. As such, it was suggested that group sizes remain small in any future running of the intervention:

*Keep group small because it is not so intimidating as a large group.*

*Limit numbers attending to under 10. Anymore and some people would feel inhibited about disclosing their feelings.*

## Session content

In terms of *the session*, it was suggested that the group facilitator confirms the needs of everyone at the beginning of the programme, as conveyed below:

*Perhaps check that everyone can hear [the facilitator] at the beginning [of the session] and be aware that not all [of the attendees] can read/write (I thought this could have been picked up beforehand)*

By confirming everyone's needs, it was proposed, that facilities could be put in place (i.e. a room away from the 'loud noise from the traffic') or adapted (i.e. use of a 'loop system'), to ensure the running of the session is as comfortable as possible for all involved. While the diverse topic areas covered by the intervention was appreciated, a number of the patients reported that more in-depth information on certain topic areas would aid people going forward:

*I attended Recipe for health and would like more information about healthy eating and nutrition. Perhaps more in-depth info[rmation] on the physicality of issues and possible solutions/treatments.*

*Felt more detail or information on managing motivation may have been beneficial.*

*I would have liked more information on how to deal with fatigue.*

The topic of 'returning to normal' was a recommended area that may be beneficial to be incorporated into the future running of the intervention:

*An exercise plan to do at home in order to get back to normal would be good.*

*I would like other workshops which will help me feel back to normal please.*

This suggestion is reinforced by the earlier theme in which the patients particularly benefitted from *changes to the self*.

#### Access

One patient noted that the intervention was a...

*'Very beneficial service offering all aspects of post cancer care.'*

...She continued to state that...

*'Support at the end of treatment is vital to mental and physical health and wellbeing.'*

Considering this, the patient proposed that the Next Steps cancer rehabilitation programme should become a standardised part of aftercare for people that are living with and beyond cancer:

*This course should be accessed by everyone who has been diagnosed with cancer and should form part of an aftercare service by automatic referral from hospital, oncologist, nurse.*



Table 9. Summary of the qualitative findings from each of the independent programmes

Theme	Sub-theme	Active Everyday	Friends and Family	Healthy on Hormones	Hope	Recipe for Health	Take Control
Benefits	Changes to the self	<ul style="list-style-type: none"> <li>• Self-confidence                             <ul style="list-style-type: none"> <li>- To exercise</li> <li>- To sustain exercise in life</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Self-confidence                             <ul style="list-style-type: none"> <li>- Empowerment to take control</li> </ul> </li> <li>• Sense of self                             <ul style="list-style-type: none"> <li>- Hasn't changed or depleted me</li> <li>- Old self back</li> <li>- Regain individuality</li> </ul> </li> <li>• Self-acceptance and validation                             <ul style="list-style-type: none"> <li>- What's going on in my head is normal</li> </ul> </li> </ul>		<ul style="list-style-type: none"> <li>• Self-confidence</li> <li>• Self-appreciation and kindness</li> <li>• Sense of self                             <ul style="list-style-type: none"> <li>- Self-reflection and awareness</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Self-confidence                             <ul style="list-style-type: none"> <li>- To go forward in a positive way</li> </ul> </li> <li>• Self-kindness</li> <li>• Sense of self                             <ul style="list-style-type: none"> <li>- Old self back</li> <li>- Getting to know myself</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Self-confidence                             <ul style="list-style-type: none"> <li>- Self-worth</li> <li>- Self-esteem</li> </ul> </li> <li>• Self-kindness</li> <li>• Self-reflection and management</li> <li>• Sense of self                             <ul style="list-style-type: none"> <li>- Old self and sparkle back</li> </ul> </li> </ul>
	Education and learning	<ul style="list-style-type: none"> <li>• Importance of exercise</li> <li>• Exercise techniques</li> </ul>	<ul style="list-style-type: none"> <li>• Development of knowledge and skills</li> </ul>	<ul style="list-style-type: none"> <li>• Hormone effects and symptoms</li> <li>• Treatment information                             <ul style="list-style-type: none"> <li>- Therapy, diet and exercise</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Information of where to get help</li> <li>• Psychological techniques</li> <li>• How to apply techniques to help life</li> </ul>	<ul style="list-style-type: none"> <li>• Information on activity, nutrition and well-being</li> <li>• How to apply to everyday routine</li> </ul>	<ul style="list-style-type: none"> <li>• Information pack</li> <li>• Stress, fatigue and exercise information</li> </ul>

Theme	Sub-theme	Active Everyday	Friends and Family	Healthy on Hormones	Hope	Recipe for Health	Take Control
	Enhanced health	<ul style="list-style-type: none"> <li>Physical               <ul style="list-style-type: none"> <li>- Reduced risk of injury</li> <li>- Enhanced fitness</li> <li>- Increased strength</li> <li>- Weight loss</li> <li>- Increased energy</li> <li>- Body confidence</li> </ul> </li> <li>Mental               <ul style="list-style-type: none"> <li>- Enhanced well-being</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Physical               <ul style="list-style-type: none"> <li>- Fatigue under control</li> <li>- Eating more healthily</li> <li>- Increased fitness</li> <li>- Increased energy</li> </ul> </li> <li>Mental               <ul style="list-style-type: none"> <li>- Doing and going out more</li> <li>- Stress relief</li> <li>- Time to stop and think</li> <li>- Enhanced emotional well-being</li> <li>- Boosts morale</li> </ul> </li> </ul>		<ul style="list-style-type: none"> <li>Mental               <ul style="list-style-type: none"> <li>- Better sleep</li> <li>- Escape overcrowded thoughts</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Physical               <ul style="list-style-type: none"> <li>- Weight loss</li> <li>- Ability to move and get out more</li> <li>- More energy and strength</li> <li>- Reduced risk of cancer reoccurrence</li> </ul> </li> <li>Mental               <ul style="list-style-type: none"> <li>- Positive, relaxed, content</li> <li>- Feel happier and in more control</li> <li>- More open and willing to take opportunities</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Mental               <ul style="list-style-type: none"> <li>- Well-being</li> <li>- More positive and happier</li> </ul> </li> </ul>
	Intent for behaviour change			<ul style="list-style-type: none"> <li>Increase exercise</li> <li>Improve diet</li> </ul>	<ul style="list-style-type: none"> <li>Work on diet and activity</li> <li>Apply psychological techniques</li> </ul>	<ul style="list-style-type: none"> <li>Goals around diet and activity</li> </ul>	<ul style="list-style-type: none"> <li>Diet and physical activity</li> <li>Sleep techniques and mood</li> <li>Managing stress and fatigue</li> </ul>
	Enjoyment	<ul style="list-style-type: none"> <li>The challenge of exercise</li> </ul>			<ul style="list-style-type: none"> <li>Attending the course</li> <li>Topics covered</li> </ul>	<ul style="list-style-type: none"> <li>Fun</li> <li>Enjoyed being with other people</li> <li>Sense of humour in the group</li> </ul>	<ul style="list-style-type: none"> <li>Attending the session</li> <li>Listening to others</li> <li>Doing activities (i.e. breathing exercises, swimming)</li> </ul>

Theme	Sub-theme	Active Everyday	Friends and Family	Healthy on Hormones	Hope	Recipe for Health	Take Control
	Life enhancing		<ul style="list-style-type: none"> <li>• Positive about the future</li> <li>• Personal achievements</li> <li>• Facilitates recovery               <ul style="list-style-type: none"> <li>- Motivation and skills to take control of life</li> <li>- Sustainable routine</li> <li>- Confidence to maintain health</li> </ul> </li> </ul>			<ul style="list-style-type: none"> <li>• First steps to healthier living</li> <li>• Motivation and positivity for life</li> <li>• Personal achievements</li> <li>• Built into sustainable routine</li> </ul>	<ul style="list-style-type: none"> <li>• Improved quality of life</li> </ul>
	Service		<ul style="list-style-type: none"> <li>• Holistic support               <ul style="list-style-type: none"> <li>- All aspects of post cancer care</li> </ul> </li> <li>• Support at just the right time               <ul style="list-style-type: none"> <li>- The end of treatment</li> </ul> </li> <li>• Wide ranging courses of treatment</li> </ul>		<ul style="list-style-type: none"> <li>• Small group size</li> </ul>		<ul style="list-style-type: none"> <li>• Small group size               <ul style="list-style-type: none"> <li>- Comfortable to share thoughts</li> </ul> </li> <li>• Well led and organised</li> </ul>
	Social		<ul style="list-style-type: none"> <li>• Meeting people on a similar journey               <ul style="list-style-type: none"> <li>- Share experiences</li> <li>- Listening to others offers validation</li> </ul> </li> </ul>		<ul style="list-style-type: none"> <li>• Meeting people with similar experience               <ul style="list-style-type: none"> <li>- Being supported and supporting others</li> <li>- Sharing experiences</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• More able to pursue and engage in social activity</li> <li>• Meeting people on a similar journey</li> </ul>	<ul style="list-style-type: none"> <li>• Meeting people on a similar journey               <ul style="list-style-type: none"> <li>- Felt comfortable in company</li> <li>- Relatable discussions</li> <li>- Listening to others offers validation</li> </ul> </li> </ul>

Theme	Sub-theme	Active Everyday	Friends and Family	Healthy on Hormones	Hope	Recipe for Health	Take Control
	Support from professionals	<ul style="list-style-type: none"> <li>• Excellent</li> <li>• Encouraging and caring</li> </ul>	<ul style="list-style-type: none"> <li>• Patient, kind and reassuring</li> <li>• Informative and helpful</li> <li>• Someone to confide in and talk to</li> <li>• Understanding, accepting, good listener</li> <li>• Person-centred support</li> <li>• Guidance to set and monitor goals</li> </ul>			<ul style="list-style-type: none"> <li>• Informative and knowledgeable</li> <li>• Empowering and person-centred</li> <li>• Understanding and encouraging</li> </ul>	<ul style="list-style-type: none"> <li>• Stimulating</li> <li>• Understanding</li> <li>• Someone to talk to</li> <li>• Instruction and advice</li> </ul>
Challenges	The sessions	<ul style="list-style-type: none"> <li>• Hard to hear</li> </ul>		<ul style="list-style-type: none"> <li>• Hard to hear</li> </ul>	<ul style="list-style-type: none"> <li>• Some topics / areas lacking information</li> </ul>		<ul style="list-style-type: none"> <li>• Some topics / areas lacking information</li> <li>• Information not always relevant</li> <li>• Content could encourage adverse effects (e.g. self-pity)</li> </ul>
	Current health and treatment journey	<ul style="list-style-type: none"> <li>• Return or worsening of illness-require further treatment</li> </ul>		<ul style="list-style-type: none"> <li>• At a different stage of treatment to the rest of the group</li> <li>• Had a different type of, or experience of, treatment to others</li> <li>• Perceive to have different needs to everyone else in the group</li> </ul>		<ul style="list-style-type: none"> <li>• Hard to apply changes due to health restrictions and limitations</li> </ul>	

Theme	Sub-theme	Active Everyday	Friends and Family	Healthy on Hormones	Hope	Recipe for Health	Take Control
	Time		<ul style="list-style-type: none"> <li>• Course was offered too early               <ul style="list-style-type: none"> <li>- Treatment not even started</li> </ul> </li> <li>• Course was offered too late               <ul style="list-style-type: none"> <li>- Treatment finished months ago</li> <li>- Already dealt with concerns myself</li> </ul> </li> </ul>			<ul style="list-style-type: none"> <li>• Lack of time in daily life               <ul style="list-style-type: none"> <li>- To be able to implement and sustain changes</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Lack of time in daily life               <ul style="list-style-type: none"> <li>- To apply techniques long term</li> </ul> </li> </ul>
	Lack of self-confidence					<ul style="list-style-type: none"> <li>• Ability to sustain changes               <ul style="list-style-type: none"> <li>- Can still feel low</li> <li>- Can still make 'wrong' food choices</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Confronting self-doubts</li> </ul>
	Location						<ul style="list-style-type: none"> <li>• Distance away from home</li> </ul>
Recommendations	Timing	<ul style="list-style-type: none"> <li>• Increase the duration of the course</li> <li>• Increase the number of courses on offer</li> </ul>			<ul style="list-style-type: none"> <li>• Offer follow-on groups</li> </ul>	<ul style="list-style-type: none"> <li>• Increase the duration of the course</li> <li>• Continue to run more of the same courses</li> <li>• Offer follow-on groups</li> </ul>	<ul style="list-style-type: none"> <li>• Increase the duration of the course</li> <li>• Offer course earlier in treatment</li> </ul>
	Participants			<ul style="list-style-type: none"> <li>• Groups of similar individuals               <ul style="list-style-type: none"> <li>- Same phase of treatment</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• More diverse mix of attendees               <ul style="list-style-type: none"> <li>- Balance of people</li> <li>- More men</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Keep group size small               <ul style="list-style-type: none"> <li>- Not so intimidating</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Check needs of the group               <ul style="list-style-type: none"> <li>- Hearing</li> <li>- Ability to read / write</li> </ul> </li> <li>• Include family members               <ul style="list-style-type: none"> <li>- Allow partners to attend groups</li> </ul> </li> </ul>

Theme	Sub-theme	Active Everyday	Friends and Family	Healthy on Hormones	Hope	Recipe for Health	Take Control
	Session content	<ul style="list-style-type: none"> <li>• More explanation</li> <li>• End goals of exercises</li> </ul>			<ul style="list-style-type: none"> <li>• More information on certain topics and areas</li> </ul>		<ul style="list-style-type: none"> <li>• Cover more diverse topics</li> </ul>
	Environment			<ul style="list-style-type: none"> <li>• Reduce noise / make easier to hear</li> <li>- Supply loop system</li> <li>- Room away from traffic</li> </ul>			
	Access					<ul style="list-style-type: none"> <li>• More awareness of the course</li> </ul>	<ul style="list-style-type: none"> <li>• Make standardised part of after-care</li> </ul>

## Conclusions

A number of key findings have emerged from this evaluation. These are summarised below:

- The intervention appears to have been widely accessed by many patients in the area that are living within and beyond cancer, but there is an over-representation of women within the cohort.
- Patient activation increased overall by an average of 19.2%; with the majority showing increases in score ( $N=42$ , 66.7%) and level ( $N=34$ , 53.1%). In those that increased, the majority did so by one level ( $N=23$ , 67.6%), but larger increases were also seen.
- There was a statistically significant increase in patient activation, in terms of both level and score, for all patients participating in MNSCR whose data were captured.
- Elements of patient activation that supported these significant changes were related to confidence in medications, improving agency within healthcare communication, and increasing intention to sustain positive behaviour change.
- Fatigue was significantly decreased as a result of participation in the Active Every Day (AED) and Recipe for Health (R4H) programmes.
- Both AED and R4H participation improved physical activity capacity in participants and decreased central adiposity (as measured by waist circumference).
- Participation in R4H also resulted in a decrease in weight, and enhanced attitudes and intentions towards positive behaviour change.
- MNSCR provided the patients with their *first steps to a more positive and healthy life*. Contributing factors included:
  - Understanding more about themselves as people and the effects that cancer has contributed to their identity.
  - Learning and applying techniques to encourage positive behavioural changes.
  - Enhanced health (physical and mental).
  - Sharing experiences with others who are perceived to be going through a similar experience.
  - Support from professionals to encourage individuals towards a richer quality of life.
- Challenges were identified with regard to perceived limitations of participating. These were related to practical concerns, different stages of treatment, timing of enrolment, and issues around self-confidence.
- The participants recommended that the programme continues so that it's positive outcomes can be experienced by further people who are living with and beyond cancer. They added that it may also be worth expanding the current programmes to include a course relating to 'the self' and of strategies that people can learn to help them feel *'normal again'*.

These findings collectively provide substantial initial support for the utility and efficacy of this multi-faceted intervention. The quantitative findings uncover promising evidence for increases in patient activation, and key clinical outcomes that are relevant to those living within and beyond cancer. There is an over-representation of women throughout the intervention, and an over-representation of those from lower levels of deprivation. Whilst this is not un-characteristic of such intervention programmes in terms of patient sex, nor of the geographic location in terms of deprivation (15, 16), there are clearly benefits that can be gained from this intervention that should be equally accessible to all. Whilst levels of available quantitative data are relatively low, the findings indicate that participation in the intervention is beneficial in increasing patient activation, decreasing fatigue, and improving behaviour-related metrics; all of which are indicated as be key outcomes with regard

to reduced incidence and recurrence of cancer, as well as factors in reduced medical economic burden (4, 11, 17-19). The combination of decreased fatigue and increased physical function are supportive of longer term health in cancer patients, both in terms of relationships to psychological distress and immunological response (20). Importantly, the metrics of benefit do not appear to differ by patient sex, age, tumour group, or level of deprivation, suggesting that the intervention is well balanced to offer equivocal support to all groups of patients.

Findings from the qualitative component of the mixed-method evaluation support and extend the quantitative findings. Participants identified important factors that allowed them to feel like they could move forward with their lives, and start to manage their health in a more proactive and engaged way. Participation in MNSCR allowed them to do something for themselves, providing time and space to re-engage with themselves and attend to their needs as individuals. Crucially, participants were able to identify improvements in both physical and mental health as a result of their involvement with the intervention. The importance of positive behaviour change was improved not just in implementation but also in observation of subsequent physical benefit (such as increased strength and weight loss). The provision of a space where "like-minded" individuals can come together for mutual support and growth appears to be an important part of the process towards change, and as a key identified benefit. This is found in similar other programmes that are designed to support those living within and beyond cancer (15), where a unique "community" of cancer survivorship provides solidarity and common interest. Of note is a lack of reports of feelings of insecurity surrounding the exiting intervention, which is seen in other cancer patient groups in social prescription models (15). This suggests that the intervention is successful in allowing patients to feel they can move on autonomously to their next steps.

However, some challenges were also identified within the qualitative explorations. Participants spoke of some practical difficulties (such as maintaining behaviour change back in the "real world"), of feeling out of step with others in their groups (particularly where treatment-stage-specific elements were being discussed), and of not quite broaching barriers with self-confidence. There was also mention of relevance of material, with some feeling that the content was either not relevant to their cancer journey stage, or not relevant to their lifestyle and culture. Indications were given about setting out goals and expectations at the beginning of programmes, and how these may be beneficial to optimising participant experience. The importance of commonality with cancer type, stage, or treatment pathway ran through the various elements of qualitative analysis; and participants have been very forthcoming with recommendations for progress with the intervention. Of key importance, it would seem, would be to continue offering what they describe to be an "inspirational" service, with requests for extending the length of programmes and recommendations for engaging with patients much sooner after clinical treatment has concluded.

## Recommendations

1. Based on the universality of benefit across patient sex, age, tumour group, and deprivation level, continue to offer the intervention to patients, but consider broadening to other tumour groups that might also benefit. Considering how to make the intervention more accessible to men might be advantageous to widen participation.
2. Participants have voiced recommendations to offer more sessions, and to offer participation earlier on in the treatment pathway.
3. Participants identified the potential for grouping cohorts based on stage of illness and treatment. This may ameliorate some of the identified challenges in engaged participation.
4. Ensure that programmes initiate with more specific information regarding content, and that expectations on involvement, intentions, and projected outcomes are clear.



5. Consider how the intervention might be made a formal part of cancer care for all, potentially at earlier stages of treatment pathway.
6. A mechanism for standardising the collection and coding of patient data (demographic, clinical, and personal) would be beneficial to the establishment of a robust and rigorous evaluation. This would enable a solid foundation of evidence to support further commissioning decisions, and provide important insight into what is clearly an ambitious and pioneering intervention.

### Recommendations for evaluation

Whilst the present evaluation has sought to provide a comprehensive and integrated overview of the MNSCR intervention, there are elements that could be modified in order to allow an enhanced understanding of its efficacy and utility going forward. The compromise between richness of data and patient burden is a difficult balance to strike, and whilst the following recommendations have been made with this in mind, some may not be practical from a patient perspective.

1. Continue to collect further data to support a more substantial quantitative evaluation.
2. Consider the collection of other clinically meaningful data that will allow detailed understanding of salient outcomes in this population (e.g. metrics of depression, anxiety, health-related quality of life, or wellbeing).
3. A mechanism for standardising the collection and coding of patient data (demographic, clinical, and personal) would be beneficial to the establishment of a robust and rigorous evaluation. This would enable a solid foundation of evidence to support further commissioning decisions, and provide important insight into what is clearly an ambitious and pioneering intervention.
4. Carry out interviews and focus groups with key stakeholders associated with the intervention; including patients, commissioners, and programme facilitators.
5. To provide further cancer-specific information such as treatment stage and/or type that might help to identify trends in key patient outcomes.
6. In order to understand potential economic implications, scales that are facilitative of economic understanding (either directly or as proxy) should be incorporated.
7. Information concerning forward travel after intervention exit might be beneficial, particularly information regarding return to work.

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