## Title: Post-cancer treatment support program: an evaluation

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## Abstract

**Objectives:** As the number of people living beyond cancer treatment has increased, supportive post-treatment interventions have become increasingly important. The present study investigates whether participation in the Maggie's 'Where Now?' post-cancer support programme is associated with improvements in healthy eating, quality of life, self-efficacy (confidence) or cancer worry.

**Methods:** In a pre-post design, 88 people who had completed cancer treatment and were enrolled in the 7-week 'Where Now?' programme at Maggie's centres across the UK rated their diet, activity, quality of life, self-efficacy and cancer worries before and after programme participation. Programme content was coded to identify the techniques used to create change ('behaviour change techniques').

**Results:** Programme participation was associated with significant improvements in general self-efficacy (p=0.01), self-efficacy about engaging in physical activity (p<.01), quality of life (p<.01), and cancer worry (p=.04) but not with changes in healthy eating (p=.23).

**Conclusion**: Participation in the 'Where Now?' programme is associated with significant improvements in several key psychological outcomes in people living beyond cancer. The techniques most commonly used in the programme to create change were giving participants instructions about how to perform a particular behaviour, encouraging problem solving to overcome barriers and setting goals.

# What is already known on this subject?

- Individuals living beyond cancer face a number of post-treatment challenges.
- Support programmes like Maggie's 'Where Now?' can help to address these challenges.

## What does this study add?

- Participation in the Maggie's 'Where Now?' programme is associated with improvements in self-efficacy (confidence) and quality of life and with a reduction in fears about cancer recurrence.
- Participation does not change healthy eating.

## How does this study impact research, practice, and policy?

• The Maggie's Where Now? programme successfully alleviates several post-treatment challenges and the behaviour change techniques used may be beneficial to the growing number of individuals living beyond cancer.

Cancer survival rates have more than doubled in the last 40 years to around 50% of those who are diagnosed[1], meaning that more people than ever are living beyond cancer. Individuals continue to face challenges after their cancer treatment has ended, displaying increased rates of depression and anxiety[2], and an increase in negative outcomes such as higher perceived disability, increased symptom burden, and lower quality of life[3,4]. Consequently, there is a need for effective support to be delivered to people in the post-treatment period in order to address these challenges and ease their transition into long term survivorship.

Current post-treatment interventions focus largely on the provision of either psychological or behavioural support and there is evidence that such interventions may help to alleviate post-treatment challenges. For example, mindfulness-based interventions have been found to reduce depression and anxiety, fear of cancer recurrence, fatigue, pain, and sleep disturbance post-cancer treatment[5]; interventions that increase self-efficacy (confidence) have been related to reduced anxiety, better adjustment to stressful situations and improved quality of life[6]; and behavioural interventions that improve diet quality and activity levels are associated with improved physical functioning, self-efficacy, quality of life, fatigue and sleep[4].

One post-treatment support programme that includes both psychological and behavioural support is the 7-week 'Where Now?' programme offered by Maggie's centres (www.maggies.org), a third sector organisation offering cancer care across the UK and abroad. Where Now? is a manualised, group-based support programme specifically designed for those who have completed active cancer treatment. Participants are encouraged to become an 'active partner' in their life and condition and take part in sessions designed to change specific health behaviours (physical activity and healthy eating), address psychological issues (emotional wellbeing and cancer worries) and support active coping with, and management of, specific post-treatment challenges such as relationship problems, changing body image and interacting with medical professionals.

As the Where Now? programme combines multiple potentially beneficial elements but had not been formally evaluated, the current study aimed to evaluate the effects of programme participation on a wide range of psychological and behavioural outcomes (healthy eating, physical activity, self-efficacy, quality of life and cancer worry). The study also aimed to identify the techniques used within the programme to help participants make positive changes ('behaviour change techniques', BCTs)[7] so that successful techniques can be identified and recommended to other support providers.

## Methods

This study used a pre-post design to measure changes in healthy eating, physical activity, selfefficacy, cancer worry and quality of life before and after participation in the Maggie's Where Now? programme. The study was approved by the University of [redacted for blind review] CERB Ethics Review Board (CERB/2018/2/1550) and all participants gave informed consent.

Participants (n=88; 12 self-identified as male/75 as female; mean age = 53 years [SD=10]; 76% educated to college/university level) were adults who had completed active cancer treatment and were enrolled in the 'Where Now?' programme between 2018 and 2020 – at seven Maggie's centres across the UK.

Participants who consented to take part in the current research study were asked to complete the same questionnaire immediately before, and immediately after participation in the Where Now? programme. The questionnaire included measures of (1) *Demographic Factors* (gender, age, years of education); (2) *Healthy Eating* (Healthy Eating Vital Signs, HEVS[8], assessing diet quality); (3) *Physical Activity* (International Physical Activity Questionnaire, IPAQ[9], assessing physical activity over the previous 7 days); (4) *Self-Efficacy* 

(Generalised Self-Efficacy Scale, GSE[10], assessing confidence in ability to cope with challenges in general, plus questions measuring confidence in ability to eat healthily and be physically active specifically); (5) *Cancer Worry* (Cancer Worry Scale, CWS[11], assessing frequency and impact of fears about recurrence); and (6) *Quality of Life* (World Health Organisation Quality of Life Brief Questionnaire, WHOQoLBref[12], assessing perceived quality of life).

Programme content was analysed to identify the techniques used to help participants make positive changes ('behaviour change techniques' or BCTs). This involved two trained coders independently coding the content of each session within the programme against a published taxonomy of all techniques that behavioural science suggests can be used create changes in human behaviour [7].

## Results

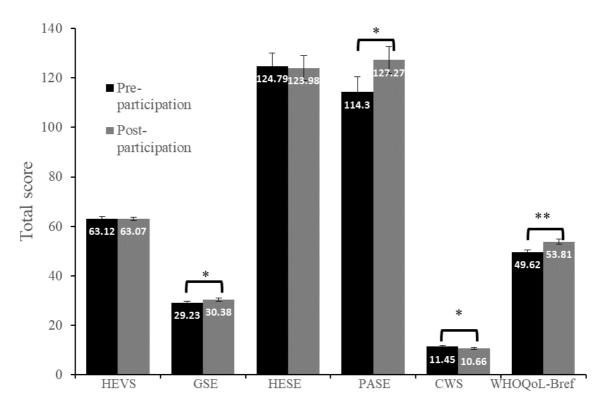
Missing data were excluded from the analysis, leaving complete data from 59-73 individuals depending on the measure. No systematic patterns of missing data were found. Responses to the IPAQ (physical activity) element of the questionnaire contained a high number (n=19) of scores indicating implausibly high activity levels which suggested that some participants had misunderstood the response scale (possibly entering weekly rather than daily minutes of activity). As a result, the physical activity data were not analysed further.

To determine whether participation in the Where Now? programme was associated with positive changes in any of the variables measured, paired sample t-tests were used to compare scores on each variable before and after programme participation (see Figure 1). The results indicated that participants' quality of life (t  $_{(67)} = -4.96$ , p <.001; n=68), general self-efficacy (t  $_{(64)} = -2.57$ , p = .013; n=65) and self-efficacy towards being physically active (t  $_{(58)} = -2.93$ , p = .005; n=59) significantly improved, and cancer worry significantly reduced

(t  $_{(72)} = 2.09$ , p = .041; n=73), after participation in the programme. However, neither healthy eating (t  $_{(62)} = -1.20$ , p = .234; n=63) or self-efficacy about eating healthily (t  $_{(60)} = -.25$ , p = .806; n=61) changed as a result of participation.

### Figure 1

Outcome variables pre-and post-participation.



*Note.* HEVS = Healthy Eating Vital Sign Questionnaire. GSE = Generalised Self-efficacy Scale. HESE = Healthy Eating Self-efficacy. PASE = Physical Activity Self-efficacy. CWS = Cancer Worry Scale. WHOQoL-Bref = World Health Organisation Quality of Life Brief Questionnaire. Error bars denote 1 SE around the mean. \*p < .05; \*\*p < .001.

The Where Now? Programme was found to contain 30 different behaviour change techniques (BCTs) that would be expected to help participants to make positive changes (Supplementary File S1). Inter-rater agreement between the two coders who coded the programme content was 0.62, rising to 1 (perfect agreement) following discussion. The five most common BCTs (with

codes from [7]) were; (1) *4.1 Instruction on how to perform a behaviour* [e.g. participants being given concrete examples of how to change a particular behaviour]; (2) *1.2 Problem solving* [e.g. participants prompted to identify barriers they might experience and methods they could use to overcome them]; (3) *1.1 Goal setting (behaviour)* [e.g. participants asked to set goals for the coming week(s)]; (4) *9.1 Credible source* [e.g. sessions facilitated by credible experts e.g. a clinical psychologist, a nutritionist, etc]; (5) *11.2 Reduce negative emotions* [e.g. participants taught techniques such as breathing and meditation to manage stress and anxiety].

## Discussion

The present study found that cancer survivors who participated in Maggie's 7-week Where Now? post-treatment support programme reported significant improvements in quality of life, cancer worry, general self-efficacy (i.e., confidence in ability to cope with challenges), and self-efficacy towards engaging in regular physical activity. As rates of anxiety and depression are typically high in the post treatment period[2] and improvements in self efficacy have been associated with a reduction in anxiety and depression[6], these results are encouraging. In line with this, earlier feedback from programme participants suggests that positive changes post-participation were attributed to improvements in confidence and self-efficacy[13]. The study also demonstrated that the Where Now? programme reduced cancer worry and improved quality of life scores. This suggests that it could be of value to people living beyond cancer. However, participation in the programme did not change diet, despite programme components focusing specifically on healthy eating.

One possible reason why the programme was more successful in changing psychological (e.g., quality of life, worry, confidence) outcomes than behavioural outcomes (i.e., healthy eating) is that at present, the programme does not include techniques that wider research suggests are important for changing health behaviours like eating and activity. For example, interventions that have successfully changed diet and activity behaviours in this population[14,15] typically gave participants feedback about their behaviour and set them graded (i.e., progressively more difficult) tasks . Neither of these techniques are present within the 'Where Now?' programme. Furthermore, healthy eating was a relatively minor element of the total programme (1 session out of 7) and so participants may not have received enough dietary support to create change.

This study has several limitations. First, it uses a pre-post design, and is, therefore, a less powerful test than a design utilising a control group. Second, issues with the IPAQ measure meant that the physical activity data could not be analysed. Third, as a result of COVID-19 restrictions introduced in 2020, the sample size was smaller than anticipated. Finally, the majority of the sample (76%) were educated to a college/university level and identified as female (85%). Lack of sample diversity is a common limitation in cancer support studies, and those with lower levels of education and/or male/non-binary gender identities continue to be understudied.

#### Conclusions

In people living beyond cancer treatment, participation in the Maggie's 'Where Now? support programme is associated with significant positive changes in quality of life, selfefficacy/confidence in one's own ability to cope with challenges, and cancer worry. However, participation does not change dietary behaviour. Designers of new support programmes should include techniques that have been associated with successful dietary behaviour change in the post-cancer population. **Funding:** This work was supported by the University of Aberdeen via research funds provided to CM and LB as part of their postgraduate studies.

**Competing Interests:** JM was employed by Maggie's at the time of data collection and was involved in the delivery of the WhereNow? programme.

**Contributorship**: CM, JA, LB & JM contributed to design, data collection and interpretation, drafting and revision of the manuscript. All authors approved the manuscript and agree to be accountable for all aspects of the work.

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#### References

[1] Cancer Research UK. Cancer Statistics for the UK. 2019.
<u>https://www.cancerresearchuk.org/health-professional/cancer-statistics-for-the-uk</u> (accessed 22 October 2019).

[2] Niedzwiedz CL, Knifton L, Robb KA, et al. Depression and anxiety among people living with and beyond cancer: a growing clinical and research priority. *BMC Cancer* 2019;19:1-8.

[3] Brown LF, Kroenke K, Theobald DE, et al. The association of depression and anxiety with health-related quality of life in cancer patients with depression and/or pain. *Psycho-Oncology* 2010;19:734-741.

[4] Smits A, Lopes A, Das N, et al. The effect of lifestyle interventions on the quality of life of gynaecological cancer survivors: A systematic review and meta-analysis. *Gynecologic Oncology* 2015;*139*:546-552.

[5] Cillessen L, Johannsen M, Speckens AE et al. Mindfulness-based interventions for psychological and physical health outcomes in cancer patients and survivors: a systematic review and meta-analysis of randomized controlled trials. *Psycho-oncology* 2019;28:2257-2269.

[6] Chirico A, Lucidi F, Merluzzi T, et al. A meta-analytic review of the relationship of cancer coping self-efficacy with distress and quality of life. *Oncotarget*, 2017;8:36800.

[7] Michie S, Richardson M, Johnston M, et al. The behavior change technique taxonomy (v1) of 93 hierarchically clustered techniques: building an international consensus for the reporting of behavior change interventions. *Ann Behav Med* 2013;46:81-95.

[8] Greenwood JL, Lin J, Arguello D, et al. Healthy eating vital sign: a new assessment tool for eating behaviors. *ISRN Obes* 2012;734682.

[9] Hagströmer M, Oja P, Sjöström M. The International Physical Activity Questionnaire (IPAQ): a study of concurrent and construct validity. *Public Health Nutr* 2006;9:755-762.

[10] Schwarzer R, Jerusalem M. Generalized self-efficacy scale. In: Weinman J, Wright S, Johnston M, eds. Measures in health psychology: A user's portfolio. Windsor, UK: NFER-NELSON 1995 35-37.

[11] Custers JA, van den Berg SW, van Laarhoven HW, et al. The Cancer Worry Scale: detecting fear of recurrence in breast cancer survivors. *Cancer Nurs* 2014;37:E44-E50.

[12] Whoqol Group. Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychol Med 1998;28*:551-558.

[13] Howells L, McMahan A, Ward A-L, et al. Where now? A survivorship course for people living beyond cancer. National Cancer Research Institute (NCRI), Liverpool 2012. Available at: <u>https://abstracts.ncri.org.uk/year\_published/2012/?s=Where+Now%3F</u>

[14] Roberts AL, Fisher A, Smith L, et al. Digital health behaviour change interventions targeting physical activity and diet in cancer survivors: a systematic review and metaanalysis. *J Cancer Surviv* 2017;11:704-719.

[15] Grimmett C, Corbett T, Brunet J, et al. Systematic review and meta-analysis of maintenance of physical activity behaviour change in cancer survivors. *Int J Behav Nutr Phys* 2019;16:1-20.

# Supplementary File 1

BCTs included throughout the intervention (ranked most to least common).

Behaviour change technique (BCT)	BCT Definition (from Michie et al, 2013)	Illustrative example of BCT within the WhereNow programme
4.1 Instruction on how to perform a behaviour	Advise or agree on how to perform the behaviour (includes 'Skills training').	Participants given concrete examples of how to change their behaviour to improve wellbeing. Including, "eating a variety of vegetables, fruits, whole grains and pulses" for the behaviour 'healthy eating'.
1.2 Problem solving	Analyse, or prompt the person to analyse, factors influencing the behaviour and generate or select strategies that include overcoming barriers and/or increasing facilitators.	Participants encouraged to use problem solving strategies to identify their own barriers to improving health behaviours and develop methods to overcome them.
1.1 Goal setting (behaviour)	Set or agree on a goal defined in terms of the behaviour to be achieved.	Participants set weekly behavioural goals for the upcoming week(s).
9.1 Credible source	Present verbal or visual communication from a credible source in favour of or against the behaviour.	Sessions are facilitated by experts in each area, including the Maggie's Centre clinical psychologist and a specialist oncology fitness instructor.
11.2 Reduce negative emotions	Advise on ways of reducing negative emotions to facilitate performance of the behaviour.	Multiple techniques discussed/used to reduce negative emotions, including breathing and meditation techniques.
1.3 Goal setting (outcome)	Set or agree on a goal defined in terms of a positive outcome of wanted behaviour.	Participants set weekly goals relating to the desired outcomes for that behaviour.
2.3 Self-monitoring of behaviour	Establish a method for the person to monitor and record their behaviour(s) as part of a behaviour change strategy.	Participants monitor health behaviours, including food intake and exercise levels.

8.1 Behavioural practice/rehearsal	Prompt practice or rehearsal of the performance of the behaviour one or more times in a context or at a time when the performance may or may not be necessary, in order to increase habit and skill.	Participants encouraged to bring in a healthy meal to share with the other participants at the end of each session.
3.1 Social support (unspecified)	Advise on, arrange or provide social support (e.g. from friends, relatives, colleagues,' buddies' or staff) or non-contingent praise or reward for performance of the behaviour	Participants encouraged to discuss relevant aspects of their lives to gain social support from other participants.
4.2 Information about antecedents	Provide information about antecedents (e.g. social and environmental situations and events, emotions, cognitions) that reliably predict performance of the behaviour.	Participants encouraged to think about the antecedents to episodes of unhealthy eating and stress.
5.1 Information about health consequences of the behaviour	Provide information (e.g. written, verbal, visual) about health consequences of performing the behaviour.	Participants advised about health consequences of improving their diet quality and physical activity levels.
5.6 Information about emotional consequences of the behaviour	Provide information (e.g. written, verbal, visual) about emotional consequences of performing the behaviour.	Participants advised about emotional consequences of improving behaviours.
8.2 Behavioural substitution	Prompt substitution of the unwanted behaviour with a wanted or neutral behaviour.	Participants encouraged to swap favourite foods for healthier alternatives.
1.5 Review behaviour goal(s)	Review behaviour goal(s) jointly with the person and consider modifying goal(s) or behaviour change strategy in light of achievement. This may lead to re-setting the same goal, a small change in that goal, setting a new goal instead of (or in addition to) the first, or no change	Participants encouraged to review behavioural goal(s) on a weekly basis, adapting if necessary.
1.7 Review outcome goal(s)	Review outcome goal(s) jointly with the person and consider modifying goal(s) in light of achievement. This may lead to	Participants encouraged to review outcome goal(s) on a weekly basis, adapting if necessary.

	re-setting the same goal, a small change in that goal or setting a new goal instead of, or in addition to the first.	
3.3 Social support (emotional)	Advise on, arrange, or provide emotional social support (e.g. from friends, relatives, colleagues, 'buddies' or staff) for performance of the behaviour.	At the end of each session, participants have a shared meal and discussion.
6.1 Demonstration of the behaviour	Provide an observable sample of the performance of the behaviour, directly in person or indirectly e.g. via film, pictures, for the person to aspire to or imitate.	The facilitator leads the group through a mindful breathing exercise.
9.3 Comparative imagining of future outcomes	Prompt or advise the imagining and comparing of future outcomes of changed versus unchanged behaviour.	Participants encouraged to discuss benefits they have found or could imagine would occur after improving their diet quality and physical activity levels.
15.3 Focus on past success	Advise to think about or list previous successes in performing the behaviour (or parts of it).	Participants encouraged to reflect on progress throughout the course.
3.2 Social support (practical)	Advise on, arrange, or provide practical help (e.g. from friends, relatives, colleagues, 'buddies' or staff) for performance of the behaviour.	Participants advised to bring someone with them to future medical appointments to gain practical support.
11.3 Conserving mental resources	Advise on ways of minimising demands on mental resources to facilitate behaviour change.	Participants encouraged to develop strategies to minimise the mental resources needed at their medical appointments.
15.1 Verbal persuasion about capability	Tell the person that they can successfully perform the wanted behaviour, arguing against self- doubts and asserting that they can and will succeed.	The facilitator discusses expectations of the course and helps to ease any anxieties or concerns.
16.2 Imaginary reward	Advise to imagine performing the wanted behaviour in a real- life situation followed by imagining a pleasant	Participants encouraged to discuss other benefits they could imagine would occur after improving diet

	consequence (includes 'Covert conditioning').	quality and physical activity levels.
1.4 Action planning	Prompt detailed planning of performance of the behaviour (must include at least one of context, frequency, duration and intensity).	Participants encouraged to create a detailed plan on how they can best utilise their appointments with their healthcare team.
2.4 Self-monitoring of outcome(s) of the behaviour	Establish a method for the person to monitor and record the outcome(s) of their behaviour as part of a behaviour change strategy.	Participants asked to assess and record how they feel after exercising.
5.4 Monitoring of emotional consequences	Prompt assessment of feelings after attempts at performing the behaviour.	Participants prompted to assess how they felt whilst completing the exercise behaviour.
10.7 Self-incentive	Plan to reward self in future if and only if there has been effort and/or progress in performing the behaviour.	Participants advised to create a plan for how they will reward themselves for progress made towards goals.
10.9 Self-reward	Prompt self-praise or self-reward if and only if there has been effort and/or progress in performing the behavior	Participants encouraged to self- reward for efforts made to improve their behaviours.
13.2 Framing/reframing	Suggest the deliberate adoption of a perspective or new perspective on behaviour (e.g. its purpose) in order to change cognitions or emotions about performing the behaviour.	Participants given multiple suggestions on how to reframe cognitions associated with unhelpful feelings and actions.
13.4 Valued self- identity	Advise the person to write or complete rating scales about a cherished value or personal strength as a means of affirming the person's identity as part of a behaviour change strategy.	Participants advised to write a letter to themselves, reflecting on personal strengths, skills and positive changes made during the programme.