



Evaluation of the North Staffordshire Cancer Lifestyle Project

Final Report

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Introduction

This report summarises the findings from the independent evaluation of The Beth Johnson Foundation's Cancer Lifestyle Project in North Staffordshire, which started in November 2015. This report builds upon the interim report completed in February 2017.

Background: The Cancer Lifestyle Project

Physical activity has a range of benefits for people with cancer, such as improved quality of life, improved physical function and psychosocial benefits (Sabiston and Brunet, 2012). Furthermore, physical activity and healthy eating can reduce the risk of other health conditions such as diabetes, cardio-vascular disease and obesity (Demark-Wahnefried and Jones, 2008).

The North Staffordshire Cancer Lifestyle Project was established in November 2015 with 2 years' funding from Macmillan Cancer Support (lasting up until November 2017) to provide support for people living with or after cancer. Its main aim is to increase the levels of physical activity, healthy eating and wellbeing in people aged 50+ who are living with or after a diagnosis of cancer. The Project as a whole delivers three strands of behaviour change interventions to people living with/after cancer:

1. Very brief advice - general talks at cancer support groups and other events to raise awareness and provide information on the issues surrounding lifestyle with and after cancer
2. Brief advice – 1-to-1 conversations after the talks with individuals where personal motivators, barriers and goals around lifestyle with and after cancer are discussed. Individuals are provided with brief advice/information and signposting but do not receive ongoing support from this service.
3. Extended brief intervention – ongoing 1-to-1 support for up to 12 months.

This evaluation focuses on the 'extended brief intervention' strand of the Cancer Lifestyle Project. The intervention is available to clients for up to 12 months and provides 1-to-1 support to help people achieve long-term behaviour change in order to improve their wellbeing.

Evaluation

Aims

This evaluation of the Project outcomes and processes seeks to provide an independent assessment of the impact of the North Staffordshire Cancer Lifestyle Project, and allow recommendations for practice/delivery. To achieve this, a mixed methods approach was required.

Methods

There have been three main elements to the evaluation:

1. Analysis of project data (baseline and follow-up) to examine whether participation in the Project led to an increase in physical activity, healthy eating and wellbeing
2. Qualitative data collection with clients to examine the delivery and impact of the Project
3. Qualitative data collection with providers (paid staff and volunteers) to examine the delivery and impact of the Project.

Consent to be included in the evaluation

The Project Lead at BJJF discussed the evaluation with clients near the beginning of their involvement with the Project. Each client was asked to indicate via two separate 'tick boxes' whether they gave permission for the information they provide to be used for evaluation purposes, and whether they were happy for the evaluation team to contact them in the future for further evaluation purposes.

Quantitative data collection

Macmillan Cancer Support, the commissioners of the service, specified the data to be collected routinely throughout the Project. The validated questionnaires include the Scottish Physical Activity Questionnaire; EuroQol five-dimensional, three level (EQ-5D-3L) to assess health related quality of life; Functional Assessment of Chronic Illness Therapy (FACIT) fatigue scale; and the General Self-Efficacy Scale (Macmillan, 2013). In addition, participants were asked to complete the Two-Item Food Frequency Questionnaire to estimate intake of fruit and vegetables. The Project Lead (BJJF) has completed the questionnaires with participants at 3-month intervals during the Project.

Participant demographics (age, gender, ethnicity, disability, index of multiple deprivation (IMD), education level) and cancer diagnosis were collected at baseline during an initial assessment. Questionnaire responses were collected at the initial assessment (0 months) and 3, 6, 9 and 12 months. These data were entered into

VIEWS, an online monitoring, evaluation and impact reporting network, by the Project Lead (BJF). The evaluation team were provided with access to the anonymised raw data for participants that consented to share their data, which were entered into SPSS for analysis. For the purpose of the final report, data were exported from VIEWS on 1st August 2017. Any data entered into VIEWS after this date are not included in the analyses presented in this report.

Quantitative data analysis

Descriptive statistics were calculated for participant demographics to explore the reach of the Project (age, index of multiple deprivation, education level, cancer diagnosis, time in programme). Descriptive statistics were calculated for baseline data (physical activity levels, fruit and vegetable consumption, quality of life, self-efficacy and fatigue). Descriptive statistics were calculated for the change in physical activity levels and fruit and vegetable consumption. Changes in mean outcome variables for wellbeing over the duration of the intervention were examined using a one-way repeated measures analysis of variance (ANOVA). Analyses were undertaken on an intention-to-treat basis, whereby the assumption of no change (in self-efficacy, fatigue, health rating and quality of life) was made for clients who had not yet completed a 6 or 9 month assessment. Intention-to-treat analyses (including missed/incomplete sessions) are less biased and provide a more conservative estimate than per protocol analyses (includes only those completing all sessions as intended). Analyses were conducted in SPSS 24.

Qualitative data collection

In qualitative research, the focus is on 'seeing through the eyes of the people studied', exploring the processes through which they interpret, make sense of and give meaning to their experiences (Bryman, 2012: 400). Qualitative data can help to explain and expand upon findings from quantitative data analyses because it provides insight into the wider context of how and why the intervention has impacted upon participants, from their perspective. This part of the data collection is also essential in gaining feedback about the process and delivery of the project, benefits and challenges involved, the participants' plans for sustaining a healthier lifestyle beyond the 12 months, and providers' recommendations for improving the Project.

Qualitative data have been collected from ten clients of the project to explore views, motivations and experiences in greater detail. Data collection has consisted of one-to-

one interviews, which followed a semi-structured interview guide. All interviews were conducted in a location of the participants' choice. Five took place at the participants' home, three at the University campus, one at a local community centre and one over the phone.

Initially, participants were randomly selected to take part in an interview from the list of client IDs at three time points, August 2017 (Time point 1), November 2017 (Time point 2) and May 2017 (Time 3). Anyone who had been invited/taken part in an interview at a certain time point were not included in the random selection at the subsequent time points. At time point 3, due to recruitment of clients to the Project being lower than anticipated, invitations were sent to all clients remaining on the list. Thus, all clients participating in the extended intervention (before May 2017), and consented to be contacted, were invited to take part in an interview (n = 17), with the time point at which they were invited was selected at random. See Figure 1.

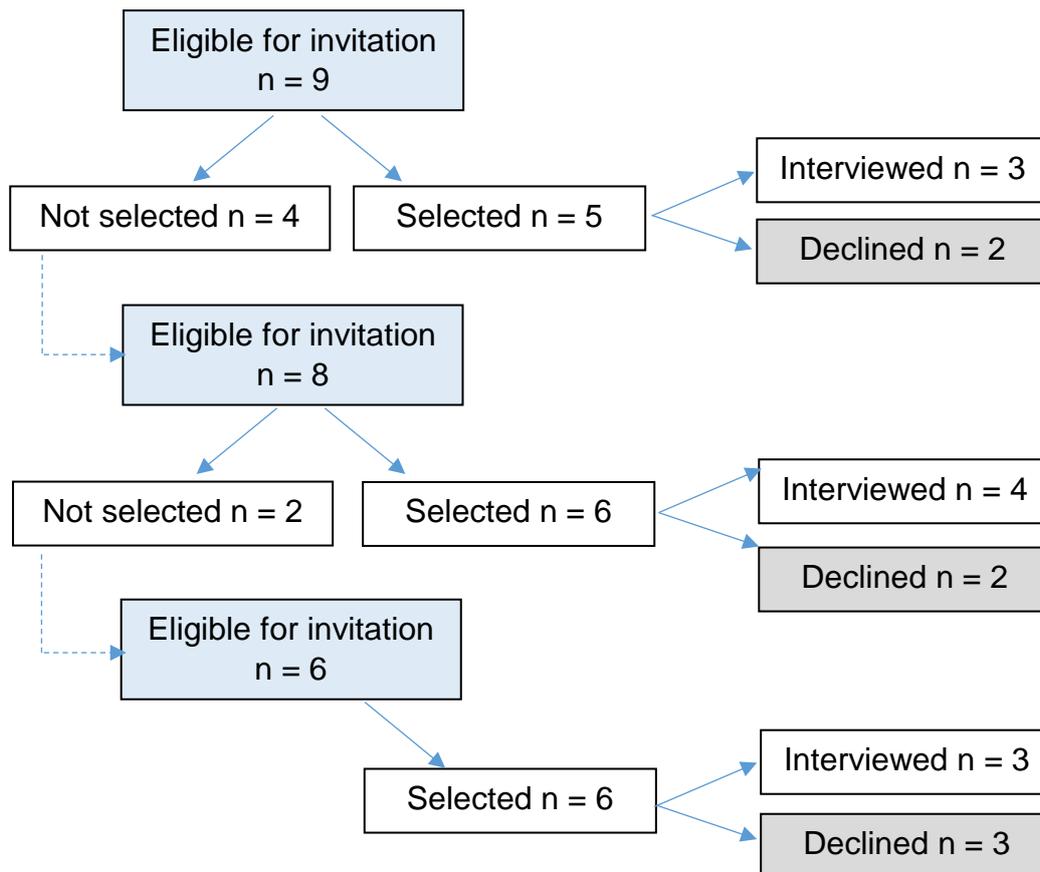


Figure 1. Flow chart of recruitment for qualitative interviews with clients

Once selected, invitation packs were sent to clients consisting of a letter of invitation and a participant information sheet. Follow up phone calls were made within 10 working days. The researcher's contact details were also provided so that the client could contact the researcher. This led to ten interviews (three at Time point 1, four at Time point 2 and three at Time point 3); over all, six clients declined to take part and we were unable to contact the other. One participant asked for their partner to join the interview alongside them.

All providers and volunteers of the Project were also invited to participate in a semi-structured interview in July 2017. Four interviews were conducted (two providers and two volunteers). These interviews lasted 38 minutes on average.

Qualitative data analysis

With participants' permission, all interviews were audio-recorded and transcribed verbatim for analysis. The client interviews were analysed separately to the provider interviews. Two thematic analyses of the data were conducted to identify, analyse and report patterns (themes) within the data. This process was guided by the aims and objectives for the evaluation and the procedure for analysis followed Braun and Clarke's (2006) six phases of thematic analysis, which includes familiarisation with the data, generating initial codes, searching for and reviewing themes, and writing up the report. The qualitative software package QSR NVivo was used for coding and to manage the analysis process in a systematic manner. To minimise any potential bias in the interpretation of the qualitative data, two researchers have been involved in the analysis process.

Results

The Project has delivered a range of behaviour change interventions to people living with or after cancer:

- 'Very Brief Advice' (general talks at cancer support groups and similar events) to 284 individuals
- 'Brief Advice' (conversations where brief advice/signposting has been provided individually following talks) to 124 individuals
- 'Extended Brief Intervention' (ongoing 1-1 support) to 35 individuals.

Quantitative data

The Beth Johnson Foundation are delivering the extended intervention of the North Staffordshire Cancer Lifestyle Project to 35 individuals currently, of which 20 have consented for their information to be used for the purpose of this report (Figure 2). Attrition rates to the programme have been low. To date, four of the participants are no longer involved in the Project as they were not contactable (n = 2), did not feel that further support was required (n = 1) or had other health complications (n = 1).

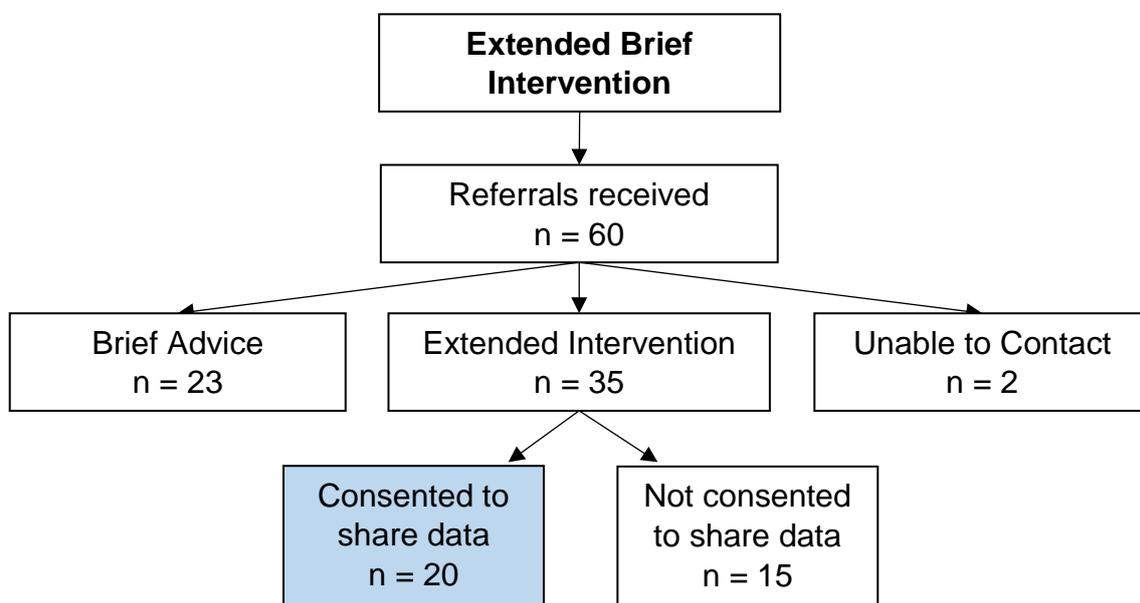


Figure 2. Flow chart of uptake to the Extended Brief Intervention

Demographics

The demographic data demonstrate that 75% of individuals engaged with the programme are women (n = 15 female, n = 5 male). The project has engaged with the target age group successfully (mean (SD) age 64.1 (8.2) yr; range 45 to 82 yr). On average, participants have been involved in the programme for 9.9 (3.3) months (range 1 to 12 months) and are currently at varying stages of the project (Table 1).

Table 1. Number of assessments participants have completed

Number	Assessment	Number of Participants
1	0-month baseline	4
2	3-month review	2
3	6-month review	8
4	9-month review	5
5	12-month review	1

A mixture of education levels existed within the sample, including a highest level of educational attainment of primary school (n = 2), secondary school (n = 5), further education (n = 8) and professional (n = 2). Data on deprivation show a spread across the deprivation quintiles (Figure 3), which reflects the range of areas from which the participants were drawn across (Stafford, Staffordshire Moorlands, Newcastle-under-Lyme and Stoke-on-Trent).

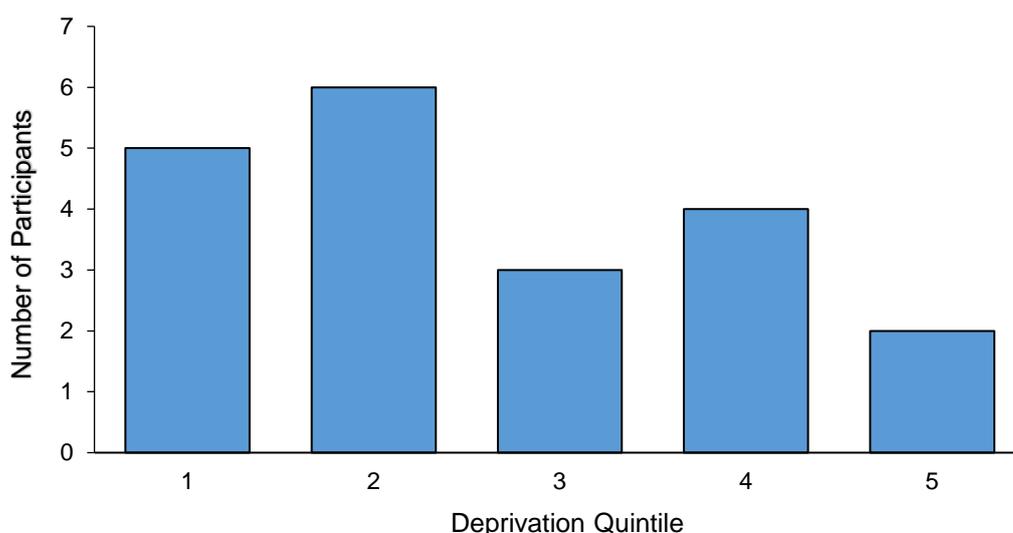


Figure 3. Sample distribution according to deprivation level of residence.

For deprivation quintile 1 = most deprived; 5 = least deprived

A large proportion of the participants self-referred into the project (n = 12). The remaining referrals were made through an Oncology Dietician (n = 3), another service ran by the Beth Johnson Foundation (n = 3), another charity organisation (n = 1) and a Clinical Nurse Specialist (n = 1).

The project has received referrals for a range of different cancers (Table 2). In terms of the status of their cancer, 65% of the participants were in remission. In the remaining participants, the cancer was localised (5%), stable (15%), advanced (5%) or unknown (10%).

Table 2. Cancer Diagnosis

Cancer Diagnosis	Number of Participants
Breast	7
Non-Hodgkin Lymphoma	3
Brain Tumour	2
Head and Neck	2
Colorectal	2
Ovarian	2
Lung, Trachea and Bronchus	1
Bladder	1

Questionnaires

The participants have been involved in the project for varying lengths of time. This section provides descriptive statistics on the questionnaires completed at baseline. As the participants worked towards individually set goals around diet and physical activity descriptive statistics of changes over time for fruit and vegetable consumption and physical activity are reported. Intention to treat statistical analyses of changes over time are shown for measures of wellbeing.

The mean (SD) and range are presented for each of the baseline questionnaires completed in Table 3.

Table 3. Baseline questionnaire scores (n = 20)

	Unit/Scale	Mean (SD)	Range
Fruit Consumption	(number·day ⁻¹)	1.5 (2.3)	0 to 10
Vegetable Consumption	(number·day ⁻¹)	1.3 (1.9)	0 to 8
Leisure Time Physical Activity	(mins·wk ⁻¹)	353 (377)	0 to 1680
Self-Efficacy	(0 to 40)	27.8 (4.9)	17 to 36
Fatigue *	(0 to 52)	27.1 (13.5)	4 to 51
Health Rating	(0 to 100)	54.0 (22.3)	0 to 90
Quality of Life	(0 to 15)	11.0 (2.2)	7 to 14

* A low score for fatigue is good. For all other scales, a high score is good.

SD, standard deviation.

The median (interquartile range (IQR)) for the number of fruit and vegetables consumed per day at each 3 month interval (for the 16 participants who remained involved with the project) are shown in Table 4.

Table 4. Median (interquartile range (IQR)) in fruit and vegetable consumption

Time (months)	n	Median (IQR)
0	16	2.5 (2)
3	15	3.0 (2)
6	14	3.0 (2)
9	6	4.0 (0)

The change in fruit and vegetable consumption between 0 and 6 months is shown in Figure 4.

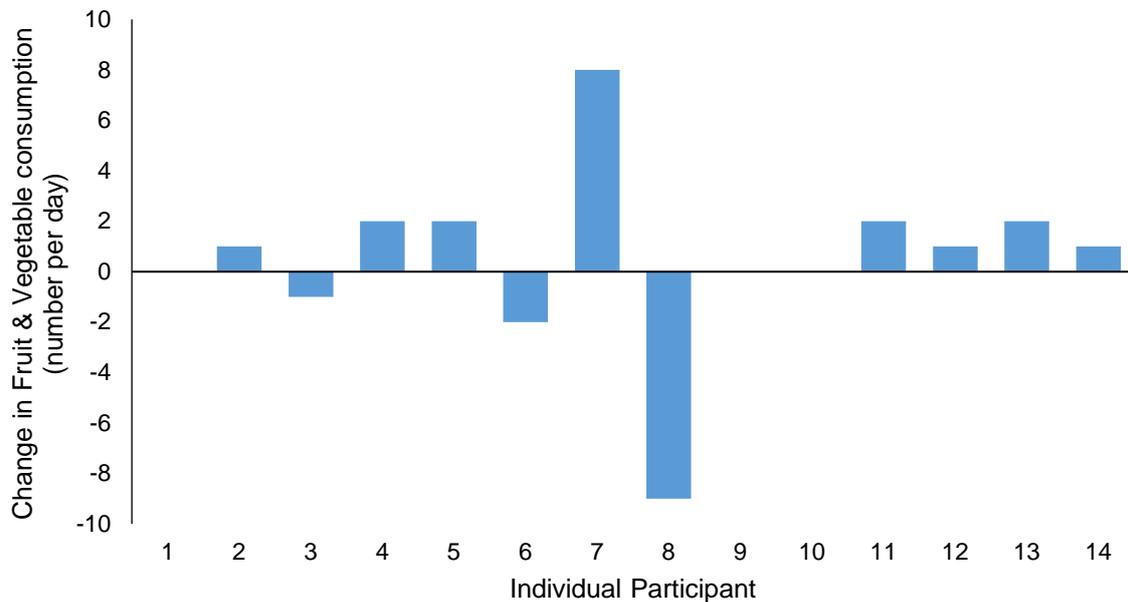


Figure 4. Individual participant changes in fruit and vegetable consumption between 0 and 6 months (n = 14).

Figure 4 shows that 8 of the participants increased, 3 participants did not change and 3 decreased their fruit and vegetable consumption. One participant (number 8 in Figure 4) had an extremely high intake of fruit and veg at baseline which explains their reduction in fruit and vegetable consumption over the course of the intervention towards a target of 5 fruit and vegetables per day.

The median (IQR) for physical activity at each 3 month interval (for the 16 participants who remained involved with the project) are shown in Table 5.

Table 5. Median (interquartile range (IQR)) in physical activity levels

Time (months)	n	Median (IQR) (min)
0	16	210 (275)
3	15	335 (353)
6	14	475 (590)
9	6	390 (368)

The median change (IQR) in physical activity levels from baseline to 3, 6 and 9 months were 90 (262); 235 (383); and 65 (185) min, respectively. The majority of participants increased their physical activity levels from baseline and maintained this over 9 months. There was large variation in changes to physical activity levels between individuals over the duration of the intervention (Figure 5). The participants that decreased their physical activity from baseline ($n = 3$) maintained physical activity levels above the recommended 150 min per week.

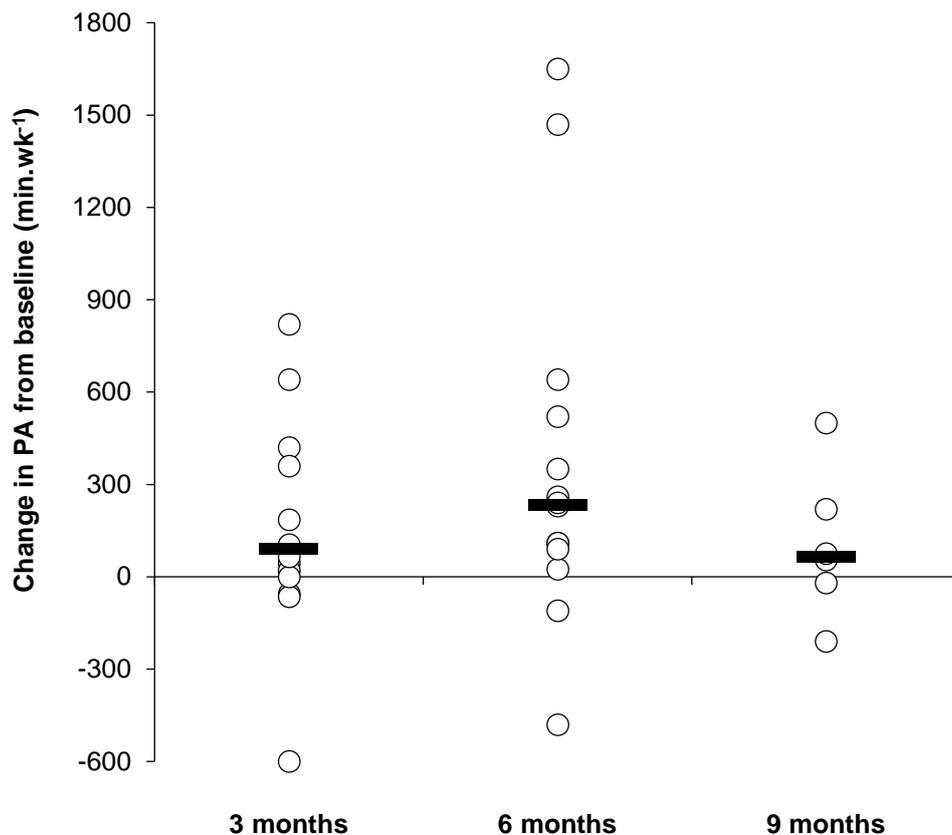


Figure 5. Individual participant changes in leisure time physical activity (PA) from baseline at 3 months ($n = 15$), 6 months ($n = 14$) and 9 months ($n = 6$). Median change in physical activity level is represented by the black bar.

Participants' mean rating of self-efficacy significantly increased between 0 and 6 months ($F_{(1.526, 25.950)} = 19.39, p \leq 0.01$). No further improvement was shown between 6 and 9 months (mean difference (95% Confidence Interval (CI)) 0.28 (-0.06 to 0.61), $p = 0.10$) (Figure 6).

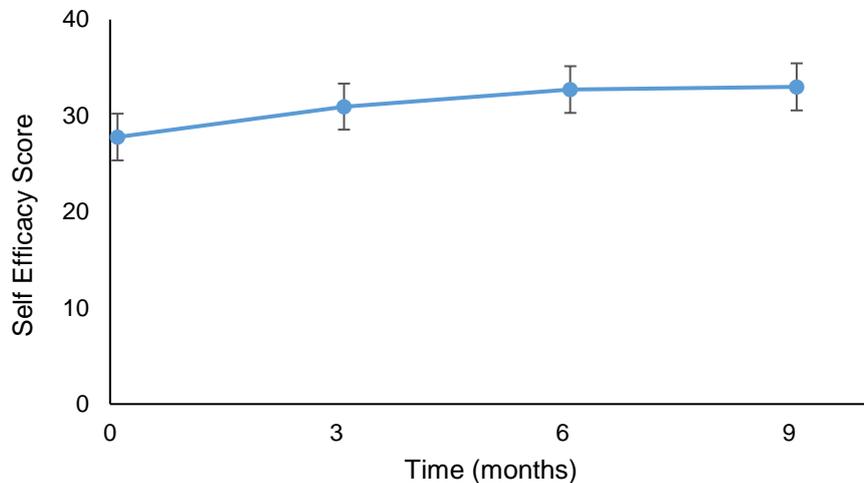


Figure 6. Mean (95% CI) self-efficacy score at each assessment point (n = 18).

The one way repeated measures ANOVA showed a significant reduction in levels of fatigue ($F_{(1.52, 28.91)} = 17.47, p \leq 0.01$), (Figure 7). Post-hoc analyses showed a reduction in levels of fatigue from baseline to all future time points ($p \leq 0.01$). The change between the 3 and 6 month / 6 and 9 month assessments did not reach significance ($p = 0.05$ and $p = 0.06$, respectively).

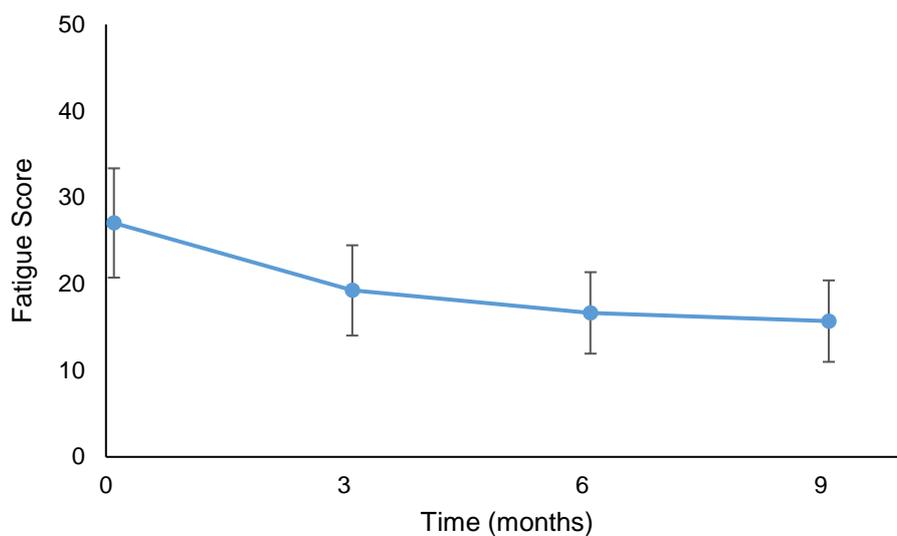


Figure 7. Mean (95% CI) fatigue score at each assessment point (n = 20).

Participants' health rating improved over the intervention ($F_{(1.45,27.60)} = 4.3$, $p = 0.03$), (Figure 8). Post-hoc analyses revealed a significant change between 0 and 6 months / 0 and 9 months and 3 and 9 months (mean difference ≥ 6.9 units, $p \leq 0.04$).

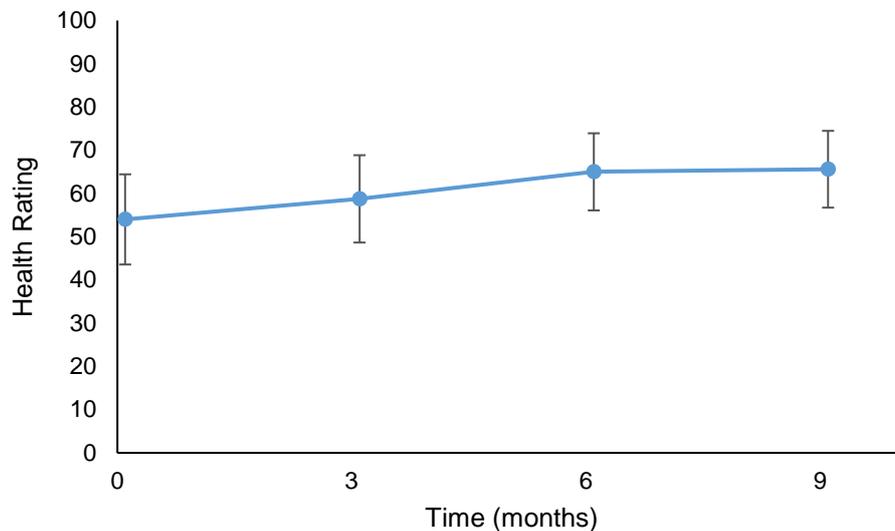


Figure 8. Mean (95% CI) participant health rating at each assessment point (n = 20).

The one way repeated measures ANOVA showed a significant improvement in quality of life ($F_{(1.42,27.04)} = 7.17$, $p = 0.01$). Post-hoc analyses showed a significant increase in quality of life at each time point from baseline (mean difference ≥ 0.9 units, $p \leq 0.01$), but no further increase between months 3 and 9 ($p \geq 0.15$) (Figure 9).

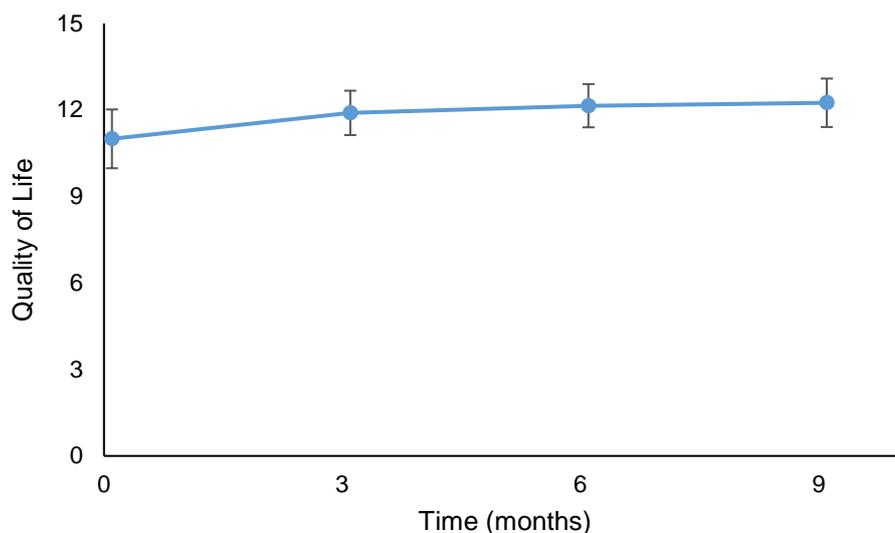


Figure 9. Mean (95% CI) quality of life score at each assessment point (n = 20).

Qualitative data – Clients

To contextualise the qualitative data provided here, this section begins with a brief description of the clients who were interviewed. The sample comprised seven women and three men. Participants were aged 45-76 years and had been involved in the project for varying lengths of time, ranging from six weeks to nine months approximately. Different types of cancer were also captured in the sample, including, for example, breast, non-Hodgkin lymphoma and bowel cancer. Six were in remission or cancer free, but as will be explored below this did not mean their lives were no longer affected by cancer.

1. *Adjusting to life with/after cancer*

A prominent theme in clients' accounts was that life after cancer is 'different' to life beforehand. Clients identified a range of changes that they faced, including fatigue, a lack of stamina and lack of general fitness. Indeed, fatigue was described as one of the hardest aspects, and that because they no longer 'look ill' (E003), it can be hard for other people to understand. This related not just to friends and family, but also medical professionals:

"The cardiologist was lovely, he understood completely, whereas the GP no, it was just 'you have finished the treatment, that's it, you are back to normal, off you go'" (E007).

Having to adapt to these changes and come to terms with not being able to do what they used to be able to do was highlighted as a challenge by clients. For some, this was often expressed as a source of frustration at least initially:

"I have always been very independent and I have always done my own thing... and I found that really hard, the fatigue and I just couldn't get up off the sofa" (E003).

"It's very frustrating when you can't do what you used to be able to do. Very, very frustrating" (E007).

Participants often talked about wanting to 'get back to normal' as soon as possible after their treatment, with the expectation that once they had completed their treatment they could be completely 'cured'. However, all participants talked about needing to adjust to life post-treatment. For example:

"I want to be the person I was before but that doesn't seem to be, it stays ... you are not going to be the same person because it has had an effect" (E007).

"There are compromises, which you have to make which is to do with fatigue and accepting what you can do now rather than what you used to be able to do. You have to be accepting really. That's the main thing. It does damage your body" (E004).

Clients also talked about physical changes that continued to impact upon their lives. These included changes to muscle tone, weight gain and the physical effects of surgery. In terms of weight gain, some clients talked about finding it harder to lose weight than they had previously for a range of reasons, including the medications they take as well as wanting to 'treat themselves' after what they had been through. For the clients who had mastectomies following breast cancer, there was a clear sense that trying to come to terms with the visible effects was something they continued to struggle with:

"When I have had a shower or anything and I am in my bedroom getting dressed and I look at myself and think 'God you look vile'. Not just because I have put weight on, because of my scar and do you know what I mean?" (E006).

"It is hard to go over, because I can't accept how I look and that's my problem, I can't look at myself, it is disgusting" (E005).

Indeed, trying to come to terms with the emotional and mental aspects of living with/after cancer was also difficult for some participants. As highlighted in the extracts below, this could present more of a challenge than the physical aspects of cancer:

"The Cancer is, physically it is draining, but mentally it is so much worse and it just messes all your head. The treatment and everything just... it's a mental struggle. For me it was more mental than physical, because physical it is just everyone expected you not to be well" (E003).

“My confidence and all that had gone, I just didn’t feel myself and even though I am working and that, I don’t know I’m just not the same person any more” (E006).

There was a clear sense from clients that ongoing support to help them adjust to life after cancer/treatment was not something that was offered routinely within the hospitals or treatment centres. This is highlighted in the following quotes:

“You do feel a little bit abandoned when you leave the hospital, which I wouldn’t have thought that would have been the case, but you do. When the treatment stops and the support isn’t there” (E007).

“You know it is true sometimes when they say like you don’t ever get over Cancer. When I went to see my surgeon after I had had my operation and I said I couldn’t believe I got Cancer like and he said ‘you had Cancer, it is done, it is gone’; but it hasn’t for me” (E002).

“It seems strange after you have had a heart attack or stroke or brain tumour or something that you have a recovery programme but with Cancer and chemo you get zapped and they just expect everything to go back to normal but it isn’t that simple, as I found out” (E004).

“You don’t get this information from the hospital. They are very good, don’t get me wrong ... but all they are interested in is the Cancer, what type it is, what treatment you are having and you know what is going to happen next. You don’t get any information as to lifestyle” (E009).

However, some clients did talk about being referred by their GP or consultant to a psychologist, therapist, dietician and a lifestyle gym. They reported mixed experiences and some issues were raised about the difficulty in getting a referral and needing to be pro-active to achieve one, and that the courses could be quite short term and any benefits being hard to maintain. Moreover, one client raised that because she did not have other health problems at the time, she got the impression that there was no point in continuing to see them. In addition, there was a general sense that advice on healthy living and making changes to their lifestyles post treatment was not routinely discussed following treatment. This was an important finding in relation to what the Cancer Lifestyle Project offered clients and explored in the next section.

2. Delivery of the Cancer Lifestyle Project

From clients' accounts and the way they talked about the Project, they appeared to be very happy with the delivery of the Project. This section explores clients' views of the Project in more detail, including what they were hoping to achieve and how they felt when they first joined.

2a. Feeling supported

Clients were very positive regarding the support and help provided. For the majority it presented an opportunity to learn and gain practical advice that could help improve their lifestyle in terms of physical activity, diet and/or wellbeing:

"Knowledge is great, you know what I mean. Now if someone can come here and sit down and go 'I've got some ideas here for you' you sit and listen and take it all in so that is brilliant" (E001).

Some clients described feeling 'stagnant' and 'at a standstill' before joining the project and were grateful to have the opportunity to work with someone to try and move things along:

"I was just glad I was in touch with somebody who I thought could help me progress because I have grown quite stagnant" (E002).

"I was grateful for the rope; to grab on a rope is the only way I can describe it. To do something" (E005).

"I think I had just come to a stop. I thought I had done everything I could do on a sort of day to day.... I just needed some more targeted help really. There was nothing else I could do" (E004).

"Well I just wanted somebody to help me with how I could move forward really from this black hole" (E009).

Clients all talked about the process of joining the Project as straightforward and flexible and were happy with the frequency of meetings with the [service deliverer], highlighting that they always felt they could pick up the phone in between appointments as well. They also liked that the Project lasted for 12 months and felt that would allow them to work towards and achieve longer term goals and help them to really embed lifestyle changes.

“I loved the idea of the year because it is a long process ... I think that is a form of security as well knowing that you are not just going to be dropped after a few months because this sort of thing takes a long time” (E010).

On the other hand, a few clients highlighted that if they felt they had achieved what they wanted to achieve before then, they might finish earlier so that someone else could benefit from the Project.

Indeed, the meetings with [service deliverer], and generally working with them, were framed in a very positive light. Clients clearly valued the relationship they had built up and described [service deliverer] as professional, friendly, amenable, easy to talk to and helpful. The ‘motivation and steering’ (E003) succinctly sums up what participants seemed to like most about the one-to-one sessions. The ‘steering’ related to getting practical advice and tips about how to make healthier choices:

“It is quite nice having someone say ‘you are doing alright you know, but what about this, what about that?’...It has been practical advice, down to earth practical advice is very useful sometimes, especially when you are looking at the big picture, you just need someone to say well let’s just, one step at a time” (E002).

“It has just helped me with the final pieces in the jigsaw I think” (E004).

That the support and advice was personal to them and built around their individual needs and interests was also valued by participants:

“Yes it is made to fit and I didn’t feel like it was ‘we are asking questions, we need the answers’, it was more of just a conversation and now I see it as a conversation with a friend almost, which is nice” (E002).

“She helps, she sits and she listens and she tries to find a way forward for you. She tries to sort out that particular issue that you have got at that particular time and she is very good at that” (E009).

Getting professional and impartial advice was also considered positive, as the quotes below demonstrate. It helped clients feel ‘safe’ and that they were less likely to do themselves ‘an injury’:

“For me it has given me a bit of clarity as regards gym work because obviously I didn’t want to go to a gym and do myself an injury. I wanted to make sure it was specifically targeted for what I need rather than just a general thing really” (E004).

“It’s nice to talk to somebody who is not a family member who is just completely impartial and, I don’t know, it’s not the support group either, it’s somebody hasn’t been through it but, just impartial sort of advice” (E007).

There was also a clear sense that having someone to look out for you was also appreciated, as the following participant describes:

“[Service deliverer] makes it sound simple and yet there is somebody caring for you like. That’s how I look at it. [Service deliverer] cares about seeing me go forward” (E002).

Another aspect of the Project that was framed positively was that it could lead to getting other types of help from BJJ/elsewhere. For example, getting advice on financial matters and the support available as well as advocacy support were identified as valuable for those living with/after cancer.

2b. Goal setting

Clients talked about the goal setting aspect of the Project in largely positive ways. That it gave them a focus/target to work towards and were broken down into small, manageable tasks were particularly helpful to participants. For some, the focus was primarily on physical activity such as attending the gym, walking more, or going swimming. For others the goals focused more on healthy eating, including eating more fruit and vegetables, managing their portion sizes, cutting down on sweets/cakes, and completing ‘food diaries’. For other clients, the focus was more on goals related to their emotional and mental needs, such as improving self-esteem, building confidence, or joining a group; for these clients in particular, the therapy side of the Project seemed to be highly valued. For most clients, their goals consisted of a combination.

Some participants talked about having to be ‘reigned in’ by [service deliverer] initially as they were trying to be too ambitious too quickly with their goals. This highlighted the importance of the dialogue. That their goals were set together, in discussion

between the clients and [service deliverer] came through as a strength, as highlighted in the quote below:

“I was happy with them, we set them together. [Service deliverer] made a suggestion and then we tweaked them and they weren’t unachievable goals, they were sensible goals, small steps” (E007).

Clients seemed to appreciate having a sense of control over what their goals would be and this was another important aspect of the Project, that people’s goals were set around their own needs and interests. For example, some talked about being told about the healthy eating workshops or sent leaflets for walking groups and deciding themselves that they did not necessarily want to go down that route. They valued [service deliverer]’s role as a facilitator, providing information, ideas, encouragement and support.

That is not to say though that clients always met their goals or indeed found them easy, as the following three participants describe:

“I find it hard but I need to do something” (E005).

“I can’t say I am achieving it every day but it is there in the back of my mind. I am thinking about it rather than just going on willy nilly, I’m actually thinking about it. I do feel different” (E002).

“I did find them a little bit of a challenge but I think you need a little bit of challenge because you are down at this level and I was determined to get better because I was actually really, really low” (E010).

For many though, including the clients above, setting and working towards their goals was linked to a positive feeling of difference since joining the project.

2c. Barriers

Clients described a range of barriers for them in relation to meeting their goals. For example, pain and deteriorating health, other conditions flaring up, lack of time due to family and work commitments, and feeling down were all highlighted. Where swimming

was a goal for clients who had had mastectomies, another challenge arose around negative feelings about their bodies. The practicalities of getting changed into a swimming costume in the presence of other people was something that these clients described as a huge challenge and one that they did not quite feel 'brave enough' (E005) yet. In addition, getting appropriate swimwear was also described as needing consideration because they were not necessarily available locally and could be expensive. However, it was highlighted here that they were relatively new to the Project and that ultimately, that is what they were working towards by the end of their 12 months' with the Project.

Another set of barriers was identified around the location and convenience of the gym and the healthy eating sessions on offer through the Project, this is discussed further in Section 3 of this report. Some clients talked about being interested in the workshops and/or gym but that they were not near enough to where they lived:

"I don't drive and they're too far away. You're talking two buses..." (E006).

One client also raised a need for more consistency in relation to the gym sessions in order to feel a physical benefit. It was also acknowledged that funding could be a further barrier to the gym aspect of Project delivery.

2d. Perceived impact

For most clients, it seemed less a case of changing their views about healthy lifestyles and more about helping them to translate that knowledge into action. Many clients talked about always having been aware of the need for a healthy and active lifestyle but that [service deliverer] has helped them to put that knowledge into practice. For clients who had completed food diaries as part of the Project, they did talk about it changing their views because they had previously not really been aware of what/how much they were eating. Indeed, that was framed as a very useful exercise by the participants involved.

In terms of impact, some clients talked about how it was hard to say at this stage as they had not yet completed the Project. Another client talked about feeling better in herself since starting the Project, but highlighted that it was difficult to attribute how much of that was a direct result of the Project.

Meanwhile, some clients talked about increasing their levels of physical activity and/or improving their diet in line with their specific goals and targets. One client explained:

“because I have been doing this [Project] on a regular basis, I can do things better, I can walk for longer, I can exercise for longer, the garden is starting to look like a garden. So that also helps you know and taking control of your own health and welfare as well and your own household” (E009).

For some clients, a social benefit was also described where they had joined a group and/or developed a walking route via friend’s house to meet up with them as well.

Over all, clients seemed optimistic for the future and many talked about feeling excited and looking forward to see what the next set of goals would be for them. Some talked about developing their own techniques for helping to increase their activities levels or manage their diet and there seemed to be genuine pleasure in this and they were excited to share this with [service deliverer] at the next meeting. For example, two clients had identified opportunities to volunteer, whilst others had set themselves targets for distances to walk/swim in between the meetings with [service deliverer]. This appeared to be a key success in developing capacity and a sense of control for clients, to move forwards with their own ideas and become more pro-active themselves with regards to maintaining a healthy lifestyle.

Indeed, the way that project was delivered generally was described as proactive and empowering in a way they had not encountered elsewhere:

“Our experience has been that there has not been a lot of proactive stuff in the other areas. Probably this is the only involvement with anything that has been proactive in that way to help people I think feel a little bit more empowered with that one on one support like that, can help” (E001’s partner).

“I feel once I have got the knowledge I can manage it myself” (E004).

Providing clients with reassurance with what they were doing was also considered empowering:

“Again, to have someone affirm what you are doing, you know it’s only small but it is affirming and it is empowering because we don’t get that sort of advice from the doctors and the hospital” (E001’s partner).

3. Potential improvements

Over all, clients reported being very happy and satisfied with the Project. When asked how the Project potentially could be improved in the future, some responded that they could not think of anything that would make it better. For those who did identify areas that could be developed, one of the most common responses related to increasing publicity and diversifying the way people could be referred into the Project. This is illustrated by the following quotes from two clients who felt that people could be missing out on a valuable opportunity because they are not aware that it is available:

“It would be useful if, I have only met [service deliverer] through chance...whereas if it had been offered through I don’t know through the Hospital or I don’t know through the Health Service it would probably have been a lot better” (E007).

“I am wondering about other people; say if somebody else hadn’t gone to the meeting and they were in a similar sort of position to me. How would they have been referred and got the same help, because I think it has just been so important” (E010).

Similarly, it was suggested that links could be made with hospitals, particularly in chemotherapy and radiology departments, as well as GP surgeries to publicise the Project and make more people aware. One client described how the Project could only have been improved through being made aware of the Project sooner:

“The only way they could have improved it was for me to do it three months before. Three months sooner... I felt that the hospital should have had more information about these things and given it you and you know explained to you that you will feel like this, you will feel like tired, you will feel fatigued and you can’t exercise, but you need to start and do it, and here is somebody who will help you to do it. Here’s the details” (E009).

There was a sense from other participants too that there had been a lack of information available to them about healthy eating and physical activity post treatment. For example, one client talked about having to ask health professionals what was available and that, for her, she would have liked to have been told about the Project sooner after finishing her treatment:

“I think really if you know you are ... going to recover with time then I think the more general advice they give you about keeping well and keeping fit the better. You have to work within your own body. Sooner rather than later really” (E004).

As mentioned previously, another set of suggestions focused on the location and convenience of the healthy eating workshops and the gym that are on offer through the Project. To some extent, this is perhaps inevitable given the geographical area covered. Whilst this was a barrier for some clients, others were happy to travel further to the gym, but highlighted that it might take longer for them to get round to arranging an appointment as a result. Another client highlighted that they did not necessarily plan to stay with the gym, but that once they had a programme agreed then they would take it to a gym nearer to them.

The final set of suggestions related to aspects that clients thought might have been involved when they heard about the Project and were not, but that they felt they would be useful to consider in the future. These related to more information specific to the cancer they had and other people’s experiences post-treatment, and on the nutrition aspect of improving lifestyle changes. One client also highlighted that she would value a social component, where people with similar experiences could come together locally:

“One of the biggest fights is when you are on your own. When you are on your own. I like it when people have got experience” (E002).

Qualitative data – Providers

The sample consisted of four women who delivered or volunteered with the Project. They have been involved with delivery for varying lengths of time, ranging from initial development of the programme (i.e. 2 years) to more recently for 6 months. Employed staff (n = 2) were responsible for designing and publicising the Project, networking with local contacts, completing questionnaires with clients and setting goals with the clients. The volunteers (n = 2) provided interim support to help clients reach their goals. For the purpose of this report, the term providers will cover both employed staff and volunteers working on this Project.

1. Project Identity

The providers believed that the Beth Johnson Foundation's Cancer Lifestyle project was unique because of its holistic approach to providing support. They explained that whilst working towards their funder's objectives around physical activity and healthy eating in relation to living with and after cancer, the Project was also able to provide additional support for their clients' wellbeing. The providers believed the Project to be unique to the local area because of the person-centred approach. Each client was considered to be an individual and received their own package of support tailored to their needs, specific goals and desired outcomes from the Project.

"I was still able to work holistically and in a person-centred way which I think is far more useful than just going in and saying these are our objectives, this is what we need to achieve" (P001).

Another aspect of the Project that providers believed to be unique was the one-to-one support that was provided in the clients' own home:

"The uniqueness I think would be definitely the one-to-one support ... Within this area there isn't anywhere that does that one-to-one support and especially home visits as well which is quite important for my clients because people feel more comfortable in their own home" (P001).

Whilst having a distinct identity was framed as an asset to the Project, it was also linked to specific challenges. For example, one provider explained the difficulty she faced when describing the service to the public and clients:

“... because it is new; because it is unique and it is the only one anywhere in the country that delivers like this I have found it hard to develop an identity really and to be able to describe that to people..... The closest I have got is that it is a wellbeing service” (P001).

Additionally, as the project was supported by the national Macmillan physical activity team, providers suggested the assessment materials used for this Project were not entirely suitable:

“the questionnaire – on the front of it says ‘physical activity questionnaire’ in big letters and ... I think that gives a bit of a mixed message” (P001).

Similarly, the provider went on to explain that whilst receiving support from the Macmillan physical activity team, they felt *“like I don’t fully fit into that physical activity team because the project doesn’t just focus on physical activity, it focuses on anything that affects somebody’s wellbeing” (P001).*

2. Recruitment and Referrals

The Project received significantly lower recruitment rates than first anticipated. Nevertheless, the providers felt that retention of clients in the Project has been successful:

“Even though the numbers have been quite small for the people who wanted the extended intervention, actually those who have started on it, I have noticed, have continued. ... So I think the retention has been quite good” (P001).

They also explained how the Project received mostly self-referrals, which was in contrast to their expectations, *“I think we would have hoped for a lot more referrals from health professionals” (P002).*

Providers described the process of increasing referrals through raising awareness of the Project as *“extremely time intensive”*. A second provider added that they *“need to find the crucial people really that are going to keep the dialogue going” (P002).* Providers also talked about the challenge of balancing their workload between publicity, marketing, recruiting and delivering to clients:

“It has been a hard balance and it has been frustrating because I want to have more referrals but in order to do that I need to spend time with potential

referrers and promoting, but that takes away from spending time with the people who I am actually working with and doing the research and supporting them” (P001).

Another challenge identified with regard to recruitment was external organisations’ perceptions and expectations. Providers perceived trust and project longevity to be important to healthcare professionals when referring clients. Providers acknowledged that they needed to show exactly what the service was, who was offering it, and that they were reliable and credible to be trusted with patients’ care. But, with the nature of voluntary sector funding, they felt some of the health professionals may have been reluctant to engage with the service and refer their patients out of fear that the Project may not exist long enough to provide the required support to their patients. As one provider stated:

“...health care professionals may potentially think that there is lots of different services offered by charities in the area and I think they may often think ‘how long is this one going to be around for?’ Because of the way the voluntary sector works you are only funded for a particular number of years, so I think health care professionals may think ‘is this one going to be around long enough for me to refer people into’ so that might stop potential referrers engaging with the service” (P001).

3. Training and Support

The training provided to those delivering the Project was reported to be very useful, with no suggestions for additional training or thoughts on how this could be improved being made. The motivational interviewing and communication training, in particular, were spoken of highly as preparing them well and providing the necessary support. Additionally, the volunteers praised the training they received:

“The Volunteer Day, where I met the people and then the training day, which gave me a focus. ... I found them really, really, useful for me” (P004).

They reported that relevant information was provided on the day and for future reference.

“...it was very good all round and there was plenty of information available on the day. There was information for me to take home. There were

websites available that I could take away and look at, because there are other training days with other organisations” (P004).

The providers also explained that the training was useful to help them understand their role and the boundaries that they needed to observe. This was particularly helpful to one volunteer who described her concern of becoming too emotionally involved with the client. She explained how it helped to clarify exactly what was expected of them without compromising on the relationship with clients and support offered.

Service providers felt that they had enough support available within the delivery team and wider networks both locally and nationally to help them with the delivery of the Project. The volunteers reported being able to seek advice from the members of staff if they felt unsure of how to respond to a client's needs. Meanwhile, employed staff explained that support was available from local and national organisations when needed:

“There’s quite a good kind of network of people who work in the cancer services field in North Staffs so yes they have been supportive. Like I mentioned [charity], the cancer advocacy team within [local organisation] – they have been a really good source of support” (P001).

4. Perceived benefits

The providers described a number of benefits for both clients and themselves.

4a. Perceived benefits for clients

The providers reported a number of perceived benefits for the clients involved with the Project. Firstly, providers believed the Project provides social support and helps individuals feel less isolated following diagnosis or treatment. *“I suppose on a social level as well, they feel probably less isolated.”*

Secondly, there was a perception that involvement with the Project helped clients cope better with fatigue:

“The things that I have noticed from when I am doing those reports, are generally fatigue levels are coming down – which is good” (P001).

Finally, providers also felt the regular visits by staff and volunteers helped clients to maintain focus and increase their confidence in working towards their project goals and desired outcomes. One provider explained:

“I find that when I go, one particular lady, she really enjoys my visits and it boosts her confidence and it gives her a focus... It helps her to bring that focus back to the action plan that has been made for her and she will then have a sort of interim action plan” (P004).

Furthermore, providers explained that the client-centred approach and giving the client ownership of their goals might have helped to improve the clients focus and confidence:

“I find it helps her to focus on what she wants, because it's not about me. It's about me helping her to do what she wants to do in life” (P004).

4b. Perceived benefits for service providers

Service providers explained how working with clients over a 12 month period and seeing someone improve and/or change behaviours over this time was “a very rewarding project” (P004). One provider explained:

“Working with someone for that long gave me the opportunity to highlight to them that they have actually changed ... I am able to see the change in people more than I think they see in themselves and that is nice to be able to communicate that back to them” (P001).

Providers explained how the Project presented an opportunity to network and build relationships with other health professionals and organisations working with people living with or after cancer.

“I like being involved in the more strategic side of it and being able to meet with other professionals. I have developed some really good relationships with some of the nurses and the dieticians from the hospital” (P001).

The volunteers in particular explained how they had benefited from the volunteering opportunity and training provided:

“I have enjoyed it all actually it's been good, so I have particularly liked the training. ... and I have enjoyed just going out and meeting people and being able to help them a bit” (P003).

They also reported how they enjoyed being able to give something back to the community:

“It makes me feel good. It makes you feel valued and that you are doing something worthwhile again” (P003).

Finally, both employed staff and volunteers talked about how being involved in delivering the Project helped them to expand their own knowledge. One of the employed members of staff commented:

“I think I have learnt a lot about ... cancer in general and in terms of healthy eating, the impact that can have on both the risk of developing cancer but also of how healthy eating affects your immune system and just a general awareness around eating difficulties as well for people who are ill in general not just people who have had cancer. So yes I have definitely learnt a lot around the healthy eating side of things and the physical activity as well” (P001).

Meanwhile, a volunteer explained how the new knowledge was useful on a personal level:

“It also keeps me sort of on the ball and aware of things and so yeah I feel like it's valuable to me as well ... what you are helping other people with, setting goals and motivation it helps on a personal basis for me as well” (P003).

Overall, the providers enjoyed delivering the programme and believed it benefited both them and the participants. One provider concluded:

“... generally I just feel like it's a worthwhile project and it should be expanded and offered to everyone” (P003).

Yet, all the providers referred to some aspects of the Project that could be addressed to improve future delivery. These suggestions are outlined in the next section.

5. Recommendations

The main recommendations identified by the service providers concerned staff capacity and the service being linked more closely to the NHS.

5a. Capacity

Given the low recruitment rate to the Project, it was stated that *“more staff would definitely increase capacity” (P002)*. In particular, one provider explained how the work

behind the scenes takes up a lot of time when promoting and running the project and providing ongoing support to the clients. Learning from their experience of delivering the service, one provider explained that further consideration would be needed to see how additional staff would best meet the capacity demands of the Project in order to maintain relationships with services referring into the Project and clients:

“If, for example, I was just working with clients and just supporting clients and didn’t have to do the promotion side of it then I don’t know if that would be better because I need to be doing both really because the people who are referring need to know who they are referring to” (P001).

A further suggestion made to improve the delivery of the Project and aid staff capacity was to split the delivery of the Project into geographical areas. The providers suggested this would reduce travel time to visit clients. They also suggested that with increased referrals and recruitment to the Project that the scope of the knowledge and learning generated would be of great value.

“I know that we have covered the whole of North Staffordshire but I am not sure how much we have analysed what is going on in areas. That is only restricted really because of the size of the project. If we had got a five year project with three members of staff we would have been learning much more. I think it is a progression thing as well. Some of our other work that has been going on for a while is now touching some of those areas – so what is the experience of people from LGBT communities affected by cancer?” (P002).

As explained by one of the providers, whilst increasing capacity and referrals into the Project would be welcome, it is important to ensure the service provided would not be compromised.

Increasing staff capacity would also afford the Project the ability to provide further emotional support to its clients. Whilst the Project intended to provide holistic support in addition to advice on diet and physical activity the Providers found high demand for emotional support.

“We would actually want to feedback and say to a funder ‘actually a major gap that people say to us is around emotional support’ and whilst we can

do some of that we only have one full time worker and a manager paid one day a weekor whatever it is..... so we can't now implement a programme of emotional support" (P002).

The providers acknowledged the importance of the volunteers for providing additional capacity and supporting the ongoing support needs of the client. Yet, the need for greater clarity of the volunteer role was suggested to ensure appropriate individuals applied and were recruited to the role. The volunteer role appeared to be more intense than originally thought and upon reflection of delivery to date one provider suggested:

"...some clarity of what we would be asking people to do, what people would need to have themselves and what we could train them to take on. ... Nearly two years in I think we have got a bit more clarity about what that volunteering role would be and acknowledging that it is a very specialist role" (P002).

5b. Link project to NHS service

All service providers explained that they hoped the Project would continue and give an opportunity for more people to benefit from its service. One provider described how she felt the Project would provide additional support to that provided by the NHS for people living with or after cancer:

"I would hope this project will continue, because I see it as invaluable as a support to the NHS, because it is just so good for the people as an interim and extra alongside the NHS" (P004).

Another provider stated how she would like the Project to be *"ingrained in what's offered from the hospital."* Service providers believed the Project has something valuable to offer at various stages of recovery of cancer and more clients could benefit if they were offered the service at the hospital.

"...the lifestyle service could be useful – at the start of treatment, during treatment, end of life or palliative and recovery from cancer. I think they are all separate times of need that the lifestyle service could offer support to people and I think if the holistic needs assessments were carried out routinely and the hospital staff who are carrying out the assessments were more aware of this service then perhaps more trusting of the service then

*they would refer into that as a result of these holistic needs assessments”
(P001).*

Summary and Recommendations

In conclusion, the Project has engaged with the target age group successfully, and recruited a broad range of individuals with regard to sex, education level, geographical area and cancer diagnosis. Retention of participants can be regarded as a success of the Project. However, recruitment to the Project was lower than anticipated which limited the sample sizes for the quantitative and qualitative aspects of this evaluation. Therefore, caution must be taken when interpreting these results.

The evaluation shows considerable individual variation for changes in fruit and vegetable consumption and physical activity levels over the course of the intervention. This likely reflects the individualised intervention that clients received in respect to the personal goals set. The person-centred approach ultimately aimed to improve diet and physical activity behaviours, but the results are more supportive of improvements in individuals' levels of fatigue, self-efficacy quality of life and health rating. This is consistent with both client and provider perceptions of the benefits associated with the Project and suggests the holistic approach and emotional support were important characteristics of the Project. The analyses presented in this report for self-efficacy, fatigue, health rating and quality of life are conservative. For individuals who had not yet reached the 6 or 9 month assessment point, no change in their data was assumed. This may explain, in part, the plateau in wellbeing reported between 6 and 9 months.

The clients discussed the need to adjust to life post-treatment and the associated difficulties. They suggested that this Project helped to facilitate the process of adjusting to a new normal, providing support and advice not offered routinely following treatment. Delivery of the Project received much positive feedback from all clients that took part in an interview. The Project has afforded clients the chance to translate knowledge into action, following personalised practical advice and support. Furthermore, clients reported feeling empowered as a result of their involvement.

The providers discussed the uniqueness of the Project and its associated benefits, as well as the challenges with regard to recruitment. The training and support offered throughout the project was considered appropriate and useful for staff and volunteers. Providers valued the new knowledge, networks and skills they developed as a result of being involved either as a paid member of staff or volunteer.

Nevertheless, the clients and providers also suggested recommendations to improve future delivery, which are summarised below.

- Clients and volunteers had positive perceptions of the project overall and valued the relationships they had developed with the [service deliverer]. It is important for this to be maintained.
- Recruitment to the Project was significantly lower than anticipated. Consideration should be given around how to increase recruitment without compromising the service for those already engaged. Suggestions to boost recruitment included wider publicity for the Project and through making links with hospitals/treatment centres to increase awareness. This evaluation report should be used to build trust and rapport for this Project with NHS and other local organisations. It is important to highlight how this Project can meet clients' wishes for additional support and the benefits they feel they have received. This may help to increase referrals to the Project.
- Consideration of emotional/mental wellbeing, in addition to physical activity and healthy eating, should be expanded as this was valued highly by clients and recognised as in demand by providers. Additional sources of funding should be sought to enable this additional need to be met within the Project (e.g., resources/training for staff/volunteers to learn how to provide emotional support, or to recruit additional staff with this knowledge to implement a wider programme of emotional support specifically, in addition to the support around clients' lifestyle).
- The role of service providers and volunteers should be reviewed and updated, following reflection of Project delivery to date, and, in particular, ahead of recruiting further staff.
- Some clients highlighted issues with the location/logistics of the healthy eating workshops and lifestyle gym. Alternatives and/or greater flexibility should be considered. This could include, for example, DVDs/podcasts of the workshops/suitable exercises, or recipe cards/booklets containing similar

information. Additional gyms/staff in different locations could help to build reach and capacity of the Project. This relates closely to the provider's recommendation of increasing capacity in different geographical areas.

- Introducing/facilitating a social aspect to the Project is recommended. There was a sense that some participants would like to come together with other people who are going through the same experiences as them. If there is not an existing group near them to link in with, perhaps interested clients could be helped to create their own. This is likely to be beneficial to clients after they have completed the 12-month programme for ongoing support.

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