

Penny Brohn Cancer Care
Service Evaluation of
'Living Well with the Impact of Cancer'
Courses

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1 Glossary

Bristol Approach: See Penny Brohn Whole Person Approach.

Cancer journey: The entire individual cancer survivor process post-diagnosis (treatment; recovery; recurrence; end-of-life care). The cancer journey will be unique to each cancer patient and will include one or more of these stages.

Cancer type: The primary cancer site.

Clinically significant: The extent to which a health related score change translates into measurable effects within the body. For example a change in wellbeing may translate into a change in hormone levels or white cell counts, which can be measured in a clinical setting.

Disease status: The classification of the point a client is at in their *cancer journey* (e.g. primary cancer; secondary cancer; treatment completed; palliative care).

FACIT-SpEx: Functional Assessment of Chronic Illness Therapy Extended Spiritual version. A psychometric questionnaire that holistically assesses people's management of chronic illness (see *PROMs*). A total health related quality of life (see *HRQoL*) score can be calculated as well as scores for discrete aspects of quality of life (see *QoL*) i.e. physical, emotional, functional, social and spiritual wellbeing.

HRQoL: Health related quality of life. An individual's level of satisfaction with aspects of their life that can be affected by their health. Measuring HRQoL is important for informing healthcare providers and policy makers.

Living Well course: Developed by Penny Brohn Cancer Care, the *Living Well course* is the flagship course and entry point to access Penny Brohn Cancer Care services and support. It is led by experienced, trained facilitators who provide clients and their supporters with a 'tool kit' of techniques that can help support physical, psychological, emotional and spiritual health as well as addressing financial and relationship issues.

Metastasis or metastatic disease: Metastasis means the spread of cancer. The term metastatic disease is used to describe cancer that spreads to other organs or to lymph nodes other than those near the primary tumour.

MYCaW: Measure Yourself Concerns and Wellbeing. A short questionnaire to determine what concerns participants have and how they rate these self-reported concerns and their overall wellbeing (see *PROMs*).

The questionnaire also collects qualitative data at follow-up detailing what other issues or factors are currently occurring in the client's life and what was most important about their visit to the centre where they attended the *Living Well course*.

NCSI: National Cancer Survivorship Initiative. A national body jointly set up by the Department of Health, NHS Improvement and Macmillan Cancer Support to assess how cancer services can adapt to support the increasing number of people living with and beyond cancer more effectively.

PBCC: Penny Brohn Cancer Care

Penny Brohn Whole Person Approach: The Penny Brohn Whole Person Approach (PB-WPA) was formerly known as the ***Bristol Approach***. A progressive pathway of support for people living with cancer and those close to them. Developed by Penny Brohn Cancer Care, this is a unique combination of physical, psychological, emotional and spiritual support using support services, lifestyle advice, complementary therapies and self-help techniques. All courses follow the *Penny Brohn Whole Person Approach* and have been designed to work together to support and enable clients to deepen their understanding of how to live well with the impact of cancer. Courses range from half day taster sessions to five day residential retreats.

Penny Brohn Whole Person Approach model: The Penny Brohn Whole Person Approach model (PB-WPA model) comprises six components that encompass all aspects of the '***whole person approach***' when looking at the impact of cancer on the person i.e. physical, psychological, emotional, spiritual health and the impact on finances and relationships. The model underpins the ***Living Well course*** at Penny Brohn Cancer Care.

PREMs: Patient Reported Experience Measures. PREMs are used to understand a patient's views on their experience while receiving care, rather than the outcome of that care. Responses are usually collected through short, self-completed questionnaires.

PROMs: Patient Reported Outcome Measures. PROMs are used to measure a patient's health status or ***health related quality of life*** at a single point in time. Responses are usually collected through short, self-completed questionnaires. This information is collected before and after a procedure or intervention and provides an indication of the outcomes of care delivered to patients.

QoL: Quality of life. The general wellbeing of an individual on a day-to-day basis.

Qualitative: Qualitative research generally prompts answers using words and descriptions rather than numbers. Qualitative researchers aim to gather an in-depth understanding of human behaviour and the reasons that govern such behaviour. The qualitative method investigates the why and how of decision making, not just what, where, when.

Qualitative researchers typically use the following methods for gathering data: participant and non-participant observation; field notes; journals; structured, semi-structured or unstructured interviews or questionnaires; analysis of documents and materials.

Qualitative data: The patterns or themes of data, collected as words, are analysed to assess if they are an effective and appropriate representation of how participants perceived or felt something.

Quantitative: Quantitative research is a systematic method of investigating phenomena and describing it numerically using statistical, mathematical or computational techniques.

Rigorous statistical tests are used to see if the result is likely to have occurred by chance. Results that are not likely to have occurred by chance are known as being ***statistically significant***.

Quantitative data: These are any data that are in numerical form e.g. statistics; percentages.

Self-help techniques: These are techniques or methods used by people to improve their own health without professional treatment or advice. These techniques may be done individually or in a group setting.

The ***Living Well course*** introduces a range of self-help techniques that are designed to help clients build resilience by learning how to relax and manage stress, understand ways to improve diet and exercise well, explore how they can build a further support network and regain a sense of control. Self-help techniques introduced on the ***Living Well course*** include mindfulness, meditation, relaxation and imagery.

SMART goals: SMART is an acronym for Specific – Measurable – Appropriate – Realistic – Time based. SMART goals are used as part of the ***Living Well course*** to enable each client to define an action plan that directly addresses and frames their goals in relation to each of the six components of the ***Penny Brohn Whole Person Approach model***.

Spiritual wellbeing: A sense of peace and contentment stemming from an individual's relationship with the spiritual aspects of life which may, or may not be religious but involve the deeper search for personal fulfilment.

SPSS v19: Computer based programme for statistical analysis of data (see **Quantitative data**).

Statistically significant: A statistical test is carried out to determine whether a change in a health related score is due to chance or if it is more likely that the intervention has had a specific effect. When a result is described as statistically significant, it means that there is a 95% chance that the intervention is responsible for the change in scores.

Survivorship: In cancer, survivorship relates to the quality of life and state of health of a person with cancer from the point of initial diagnosis onwards. Issues related to survivorship include the physical, emotional, psychological and spiritual long-term effects of having cancer and cancer treatments, secondary cancers and the further recurrence of cancer.

Whole person approach: See *Penny Brohn Whole Person Approach*.

2 Executive Summary

The aim of the Penny Brohn Cancer Care Living Well Service Evaluation was to measure the level of benefit that participants were receiving from the Penny Brohn Cancer Care (PBCC) Living Well course and to inform current and future service provision at PBCC. The Penny Brohn Whole Person Approach model (PB-WPA model), which underpins the Living Well course, was designed to support the 'whole person' and the course was intended to meet the needs of people with cancer, as identified by the National Cancer Survivorship Initiative (NCSI)¹.

The combined qualitative and quantitative results of the Living Well Service Evaluation have demonstrated, very clearly at times, that participants were highly satisfied with the course. The immediate benefit of attending was measurable, in terms of improved health related quality of life (HRQoL) and improved MYCaW (Measure yourself Concerns and Wellbeing) concerns and wellbeing.

The evaluation results show that the Living Well course experience enabled the majority of participants to regain control over many aspects of their life, and to start taking responsibility for their health. The following aspects of the course were identified as the most helpful:

- Specific units of 'education and explanation' about cancer and why healthy lifestyle changes to areas such as diet, exercise and relaxation are beneficial
- Advice and education from medical doctors
- The opportunity to share experiences with other participants

For some, this empowerment led to long-term changes in exercise, food consumption, use of self-help techniques and the ability to communicate more freely and openly with family, friends and medical professionals. These improvements were reflected in the 12 month outcome data, where a sustained improvement in HRQoL and MYCaW concerns was reported by many clients.

Such patient reported outcome measures (PROMs) are limited in what they can measure, thus qualitative data were also collected to ensure that participants were able to share their experiences (positive or negative) of the Living Well course, and their subsequent experiences of applying the education and techniques learnt on the course.

A picture emerged that identified difficulties in sustaining lifestyle changes at around the 3-6 month follow-up. Participants who returned to PBCC within the 12 month follow-up period, however, were more likely to benefit by reporting a greater improvement in HRQoL and MYCaW scores, plus an improved understanding of how to make and maintain healthy lifestyle changes to suit their individual circumstances.

In regards to the current NCSI priorities², it is hoped that the data reported in this evaluation go some way to informing the following:

- Information and support from the point of diagnosis
- Managing the consequences of treatment

-
- Promoting recovery
 - Sustaining recovery
 - Supporting people with active and advanced disease
 - Improving survivorship intelligence

Finally, this report demonstrates how a patient-centred model of support can be effectively evaluated to provide relevant, practical and evidence-based information to commissioners.

Participant satisfaction:

- Participants were very satisfied with the course content, course delivery and resources provided which often exceeded their needs and expectations.

Participant outcomes:

- The PB-WPA model successfully encompassed and supported all the types of concerns participants arrived with.
- The most frequently reported participant concerns were psychological and emotional, about their wellbeing and about their physical health.
- On average, participants experienced statistically and clinically significant improvements in their MYCaW concern and wellbeing scores, and total HRQoL scores, which remained improved over the 12 month follow-up.
- The aspects of HRQoL that were most likely to improve after attending the Living Well course were spiritual, emotional and functional wellbeing.
- Supporters had their own profile of concerns, namely psychological and emotional, supporter specific concerns and practical concerns. Concerns were as severely rated as those from participants with a diagnosis of cancer and also showed statistically significant average improvements throughout the 12 month follow-up.
- The small group of participants with metastatic disease reported significant improvements in their MYCaW concern scores, in line with the whole evaluation group, and a significantly greater improvement in HRQoL over 12 months compared to participants with primary cancer.
- Participants who returned for more support from PBCC were in more need of support than those who did not return. They were more likely to have poorer HRQoL at baseline and rate their concerns more severely.
- Participants who returned to PBCC experienced more improvement in HRQoL that was likely to be clinically significant. These participants also had a greater degree of improvement in their MYCaW concerns, compared to non-returners.
- Over half of the participants experienced new concerns over the 12 month follow-up period. Concerns were most frequently associated with psychological and emotional and physical issues. Furthermore, at 12 months, participants were still experiencing a range of health issues.

Participant experience:

- Key features of the course which were most helpful were 'sharing with others'; 'the course in general'; 'nutrition and food'; 'the doctors' talk'; 'relaxation, meditation and self-help'.
- The majority of participants reported improvements in close relationships as a result of attending the Living Well course, which included being more open, talking more freely and placing a greater value on close relationships.
- For some participants the Living Well course helped clarify what was important to themselves, which occasionally caused further conflict within a close relationship.
- The Living Well course facilitated mutual benefits for the patient-supporter dyad, including better communication and an understanding of each other's needs, which led to more effective support. The supporters were also more likely to have an increased awareness of the importance of their own wellbeing and how to make healthy lifestyle changes.
- Many participants reported feeling more confident and able to seek help from medical professionals when they needed it.
- Some participants were empowered to take responsibility for their own wellbeing and to be more aware of the boundaries of what the NHS can and cannot offer. Approximately 50% of the original group were motivated to access their own supportive, health and community based groups and resources.
- Participants wanted a range of flexible and accessible support after attending the Living Well course, which included practical suggestions, DVD based resources, more communication from PBCC, more communication with other clients on their Living Well course and more PBCC centres closer to where they lived.

Lifestyle changes:

- Many participants found the education and experience of trying out self-help techniques on the Living Well course beneficial and reported that this enabled them to regain control over aspects of their life. There was a sustained increase in the number of self-help techniques being practised through to 12 months after the course.
- Education from the Living Well course motivated the majority of participants who were not exercising to start exercising, and for active participants to exercise more effectively. Many participants were inspired to combine physical activities with increased engagement in group-based social activities.
- The nutrition education on the Living Well course had an immediate positive impact on participants, who made noticeable dietary improvements over a period of 6 weeks – 3 months.
- Participants were often more aware of what a healthy diet consists of, although challenges to maintaining a healthier diet were most frequently reported 3-6 months after the Living Well course.

Barriers to change:

- Returning to work or a deterioration in health, often side-effects of chemotherapy, commonly led to less exercise being undertaken.
- More support from family, friends and PBCC is needed for participants to sustain initial improvements in their eating habits.
- Other challenges to maintaining the use of self-help techniques included time pressures from work and family commitments, and forgetting the techniques, often due to side-effects of chemotherapy.

3 Introduction

The number of people experiencing a cancer diagnosis and living beyond this diagnosis is gradually rising, as biomedical treatment continues to improve². Despite the levels of survivorship increasing, people on the cancer journey experience a range of issues around the long-term impact of a cancer diagnosis, for example, with their health related quality of life (HRQoL), long term effects of cancer treatments and the likelihood of recurrence and metastasis, to name only a few.

All of these issues place a heavy resource and economic burden on the NHS, which in real terms will be unsustainable as survivorship numbers increase. Furthermore, increasing awareness of the importance of the patient experience and the need to develop new models of self-management^{1,3,4,5,6} are contributing to a changing agenda for healthcare in general and for cancer survivorship.

3.1 Development of the Penny Brohn Whole Person Approach model

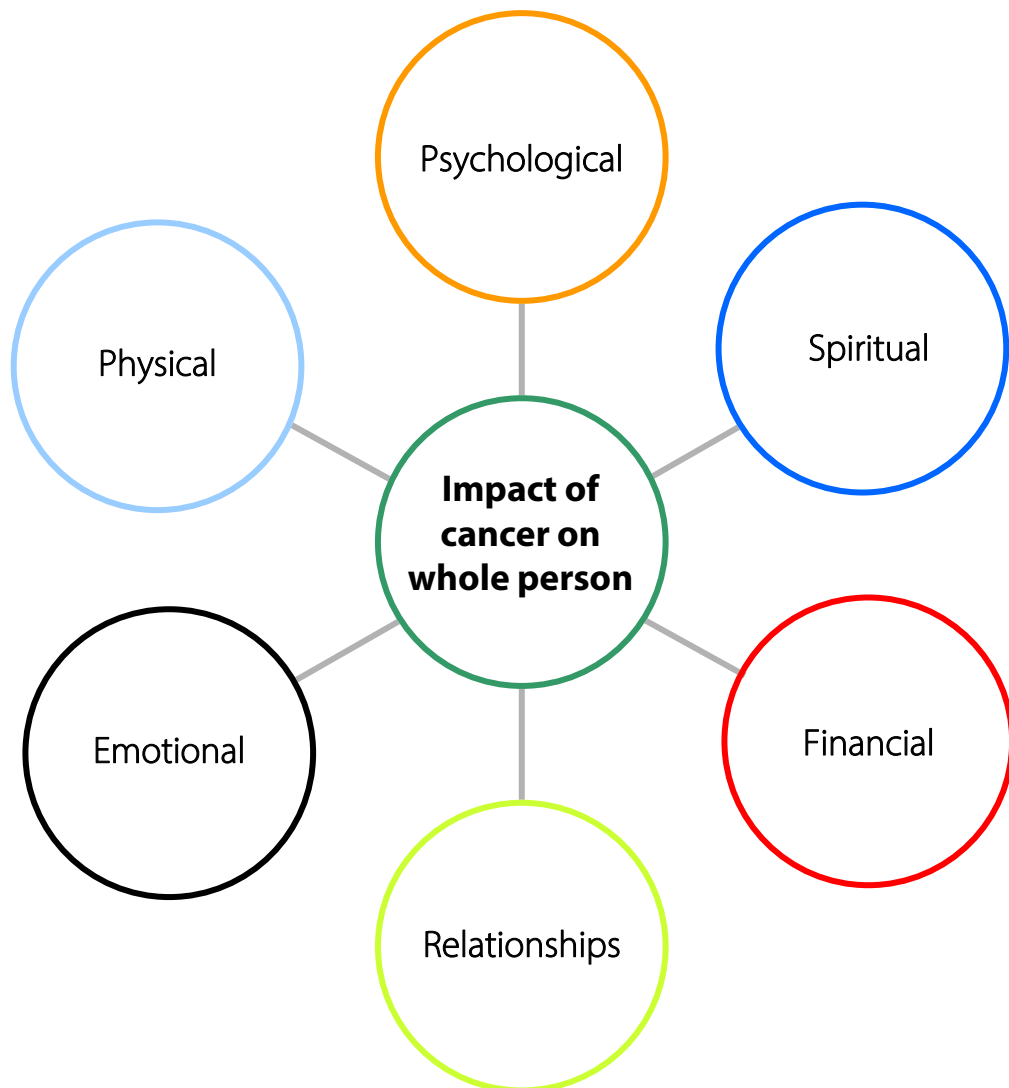


Figure 1 - The Penny Brohn Whole Person Approach model

The National Cancer Survivorship Initiative (NCSI), borne out of the Cancer Reform Strategy 2007⁷, has reviewed and collated evidence in relation to national cancer services, and identified evidence gaps on how cancer services can adapt to effectively meet the needs of the increasing number of cancer survivors^{1,2,8,9}.

Penny Brohn Cancer Care (PBCC) was a key contributor to the NCSI Living Well 'Active and Advanced' Workstream. This sub-group produced a scoping report¹⁰, which recommended people with cancer should be supported by a whole person, person-centred approach and that self-management skills should be taught as a key part of that approach. The report recommended that the NCSI should concern itself with the delivery of Living Well services, to allow the whole person to live well (physically, psychologically, emotionally, socially, financially, spiritually) instead of treating cancers in isolation from the person. The scoping report also argued for the use of 'whole systems research approaches'¹¹ in research and evaluation design, to collect data which meaningfully reflects the holistic and complex nature of interactions between healthcare provider, treatment approaches and self-management of cancer and extrinsic influences.

These recommendations were highlighted in the NCSI 'Vision' report (2010)¹, which recommended a shift towards supported self-management based on individual needs and preferences and alongside appropriate clinical assessment, support and treatments. The current subsequent NCSI report, 'Living With and Beyond Cancer - Taking Action to Improve Outcomes' (2013)² also specifically identifies six key evidence gaps that need to be addressed in relation to the provision of cancer services:

- Information and support from the point of diagnosis
- Managing the consequences of treatment
- Promoting recovery
- Sustaining recovery
- Supporting people with active and advanced disease
- Improving survivorship intelligence

3.2 The Living Well course

In response to the NCSI Vision report¹, PBCC implemented the 'Living Well' course to ensure that all clients at PBCC are offered a package of advice, information and support to help them live well with the impact of cancer. The Penny Brohn Whole Person Approach model (PB-WPA model) uses a 'whole person' approach, acknowledging that a person's wellbeing comprises many aspects¹² and therefore cancer impacts upon the 'whole person'.

The Living Well courses were designed to be person-centred and flexible to cater for the large range of clients who visit PBCC (see Table 1). The PB-WPA model content was informed by previous service evaluation data^{13,14} collected from nearly 800 clients at PBCC and The Havens (formally Breast Cancer Haven) plus over 30 years of PBCC staff experience of supporting people with cancer.

The Living Well course is the 'flagship' entry course onto other PBCC services and support. The course consists of units that can be delivered as a two day residential, three day non-residential, or two hours a week over seven weeks. The course was also designed to be delivered in a range of settings i.e. in hospitals or outreach centres away from the National Centre, in addition to PBCC's National Centre. PBCC courses are interlinked and range from half-day taster sessions to five day residential retreats. They are a progressive pathway of support for people living with cancer and their close supporters. The courses provide clients with the chance to take time to reflect on their cancer journey.

Living Well courses are led by experienced, trained facilitators and provide clients with a tool kit of techniques that can help address the six components of the PB-WPA model: physical, psychological, emotional and spiritual health as well as financial and relationship issues. Each client is provided with a Living Well handbook that is used to provide practical summaries of the learning followed, plus individual space for note taking and reflection for the duration of the course. Information and explanation of current guidelines and scientific evidence in relation to cancer is provided regarding healthy eating¹⁵ and exercise¹⁶. The impact of cancer on emotions and relationships^{17,18,19,20} is also discussed. In addition, simple but effective methods of relaxation, meditation, mindfulness and imagery^{21,22,23} are experienced as tools that participants can take away with them. Clients are encouraged to share their experiences with others in similar situations in order to break down the sense of isolation that a cancer diagnosis often brings. They are also provided guidance on how to have more choice and control over how to support themselves and are facilitated to consider what future steps they could take to 'live well' by setting achievable SMART goals to focus their efforts after leaving the course.

Further Living Well courses have been successfully delivered, with North Bristol NHS Trust running the first course held outside of the PBCC National Centre. After a series of successful pilot Living Well courses delivered around the country, PBCC is continuing to roll out a national programme of Living Well courses to meet the current demand.

3.3 Evaluating the Living Well courses

The current and future commissioning landscape will rely heavily on good quality research and evaluation to inform commissioners of the benefit of cancer support services. A shift from an emphasis on measuring clinical activity to a new emphasis on measuring experience and outcomes through routine use of Patient Reported Outcome Measures (PROMs) in aftercare services is being recommended¹. There is currently a paucity of evaluation or research data which demonstrates the short and long-term impact of the patient-centred approach to support and self-management^{24,25,26,27,28}. These data are critical for supporting the decision making of commissioning boards, as well as those currently involved in the provision and development of cancer services.

As demand for the PBCC services continues to grow, it is of paramount importance for PBCC to be able to rigorously demonstrate how the Living Well service can be measured against set objectives, in a manner that responds to the growing need to capture clinically meaningful patient outcomes, experience and satisfaction.

The Living Well Service Evaluation was carried out in collaboration with the University of Westminster. It was designed to address a number of requirements:

-
- To inform PBCC how well the Living Well course was performing in relation to the six evidence gaps highlighted by the NCSI².
 - To understand the client experience and identify any aspects of the Living Well course that could be improved.
 - To understand how the education from the course is utilised once clients finish the course and return home.

As the Living Well course is open to any person with cancer, and their supporters, irrespective of where they are on their cancer journey, the evaluation aimed to take a snapshot of all users coming onto the Living Well course over a period of five months. These participants were then followed up over a further 12 months.

The key features of the Living Well Service Evaluation are:

- Data were collected pre- and post- course, then at 6 weeks, 3 months, 6 months and 12 months subsequent to participants attending the course.
- Data were collected from 171 participants and the participant retention rate was 50% at 12 months. Participants included cancer patients and their supporters.
- Participants with cancer had been diagnosed with a range of more than 20 cancer types representing all of the major cancer groups, and at all stages of the disease.
- Quantitative and qualitative data were collected to ensure all six components of the PB-WPA model were evaluated, plus the impact of the Living Well course over time i.e. up to 12 months after attending a course.
- Longitudinal data on the intrinsic and extrinsic barriers to initiating and sustaining healthy lifestyle changes were collected to inform existing and future service development.

This report will now detail the findings of the service evaluation with a focus on the following key areas:

- The participants' experience of the Living Well course
- The short and long term impact of the Living Well course
- The impact on supporters attending the Living Well course
- Participants with metastatic cancer
- The impact of returning to PBCC for more support after the Living Well course
- Participants' ongoing needs and concerns

3.4 Methods

All clients attending a Living Well course between August 2011 and January 2012 were invited by PBCC to take part in the evaluation by letter. Ethical approval was gained from the University of Westminster and the Local NHS ethics board confirmed that this was a service evaluation.

The invitation letter contained a participant information sheet that explained the objective of the service evaluation and a consent form. At the point of consent, participants were offered the option to fill in the follow-up questionnaires as either a paper based (with return envelopes) or online version.

If clients consented to take part, a series of questionnaires (paper based) were then administered before and after the Living Well course and then at 6 weeks, 3 months, 6 months and 12 months after attending the course. Questionnaires took approximately 20 minutes to fill in. Non-responders to the questionnaires were contacted by telephone or by letter during the follow-up period to maximise the response rates.

3.4.1 Data collection - Measuring participant outcomes, experience and satisfaction

It was important to capture participant reported outcomes. The data collection methods and tools collectively captured data on all aspects of the PB-WPA model, which underpins the Living Well course, as well as participants' experiences and levels of satisfaction (see appendices for copies of the questionnaires used). The use of a range of questionnaires provided the potential to corroborate data from different sources. All data were collected at each time-point unless specified otherwise below (See Figure 2).

1. Measure Yourself Concerns and Wellbeing (MYCaW)

A short PROM to determine what concerns the participants have and to allow participants to rate these self-reported concerns and their wellbeing. The questionnaire also collects qualitative data at follow-up capturing other issues or factors occurring in the client's life and what was most important about their visit to the centre where they attended the Living Well course.

2. Functional Assessment of Chronic Illness Therapy Extended Spiritual questionnaire (FACIT-SpEx)

A psychometric PROM that holistically assesses people's management of chronic illness. A total health related quality of life (HRQoL) score can be calculated as well as scores for discrete aspects of QoL i.e. physical, emotional, functional, social and spiritual wellbeing.

3. Client satisfaction - In house evaluation form

A mixture of score rating questions and open ended questions, designed to assess client satisfaction with course content, course delivery, and the PBCC National Centre and its resources.

4. Lifestyle questionnaire

Specifically designed to collect basic data regarding diet, exercise and relaxation techniques, to evaluate the participant use and application of key information provided on the Living Well course.

5. 6 week participant experience questionnaire

Bespoke open-ended questions to identify how participants viewed the content of the Living Well course, their experience of, and effect of, utilising the information and techniques provided [6 weeks time-point only].

6. 12 month participant experience questionnaire

Bespoke open-ended questions to capture data on implementing and sustaining changes recommended on the Living Well course [12 months time-point only].

3.4.2 Data analysis

Quantitative analysis:

Data gathered either via paper or online questionnaires was immediately anonymised and entered into SPSS v19. Data was cleaned and then basic descriptive statistics were carried out to describe participant characteristics.

Quantitative scores were independently recorded over several time-points for MYCAW concerns and wellbeing, FACIT-SpEx and lifestyle measures.

Concerns data from the MYCaW questionnaire were coded as previously described^{13,14} and the categories identified were entered into SPSS as a binary score. Score changes were calculated at each follow-up time-point relative to baseline for MYCaW concerns, wellbeing and FACIT-SpEx, as well as the measures on the lifestyle questionnaire. When necessary and to ensure conservative analysis, non-parametric tests (Wilcoxon Signed Ranks) were used to determine statistical significance of change scores. To assess significant change over time, for MYCaW and FACIT-SpEx, Repeated Measures Anovas (listwise) with Bonferroni corrections, or Friedman tests were performed. Score changes for FACIT-SpEx were calculated for the total HRQoL and for the subscales, to see how each subscale contributed to the overall HRQoL. Score changes for FACIT-SpEx were then coded as positive, no change or negative, to understand the direction of change for each person. Further non-parametric post-hoc analysis was carried out if significant results were found to assess at which time-point significant changes occurred.

Qualitative analysis:

Qualitative data ranged from 1-10 sentences in response to open-ended questions from the MYCaW follow-up forms and the 6 week and 12 month bespoke participant experience questionnaires. Qualitative MYCaW data was coded by MJP, EB, HS and RJ as previously reported. More in-depth qualitative data from the bespoke questionnaires was thematically analysed by MJP to identify key themes emerging from the participants' experience of the Living Well course (6 week time-point) and experiences of their cancer journey over the subsequent year (12 month time-point). Data were coded and codes were combined to identify themes. Data were analysed further to

identify facilitators and barriers to self-managing and to sustaining the advice from the Living Well course.

The quantitative and qualitative data were combined as previously described^{13,14} to understand whether wider life events affected the degree to which MYCaW and HRQoL scores changed. Furthermore, themes from the qualitative data from participant experiences at 6 weeks and 12 months provided a framework to model the experiences of people with cancer and supporters over a one year period.

4 Results

4.1 Response rates and participant characteristics

One hundred and seventy one participants were recruited from 19 residential two day courses and three external courses running weekly between August 2011 and January 2012.

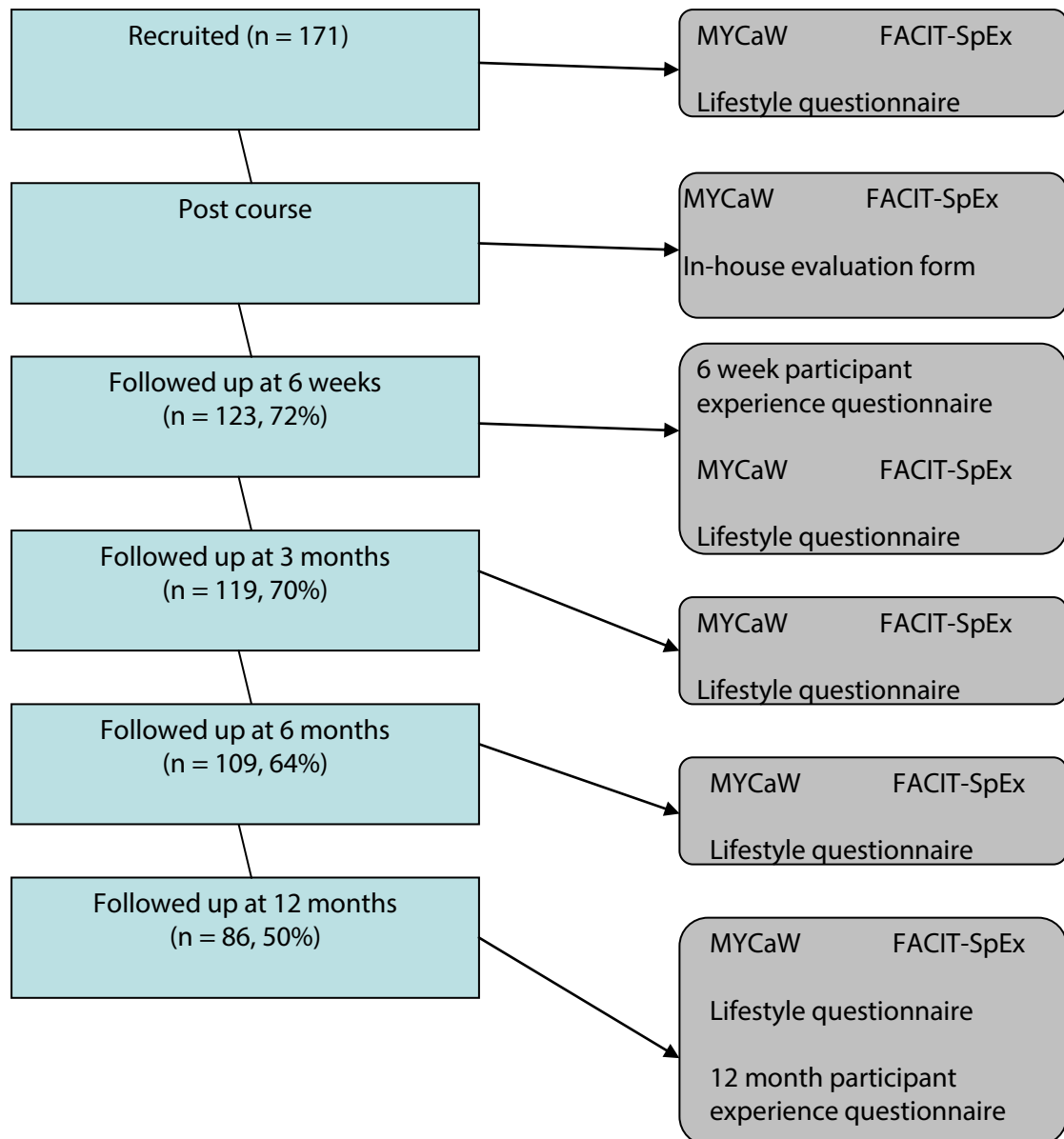


Figure 2 - Timeline, response rates and questionnaires administered at each time-point

As shown in Figure 2 above, the response rate to the service evaluation questionnaires decreased to 50% through 12 months. To understand if there was a particular reason why participants failed to respond, they were contacted after 6 months (n=79). Forty five percent responded and listed the following reasons for not completing questionnaires: too busy; forgot; family illness; felt like had nothing to say or no change; didn't want reminding of cancer experience; thought had already done it; not received

it; lost it; too ill; away from home; changed address. No issues with the quality of the Living Well course run by Penny Brohn were raised.

	Baseline (n=171)	12 months (n=86)
Male	22.8%	17.4%
Female	77.2%	82.6%
Patient	78.3%	82.4%
Supporter	21.7%	17.6%
Residential	92.9%	n/a
Weekly	7.1%	
Age		
18-30	3.6%	3.5%
31-40	7.9%	9.4%
41-50	27.3%	27.1%
51-60	35.2%	31.8%
61-70	20.6%	24.7%
71-80	4.2%	2.4%
81+	1.2%	1.2%
Cancer type*		
Breast	54.0%	57.7%
Lung	2.9%	1.4%
Bowel	9.5%	5.6%
Prostate	5.8%	8.5%
Gynae	7.3%	11.3%
Other	14.6%	14.1%
Disease status*		
Primary treatment	51.1%	9.1%
Finished treatment	21.2%	62.3%**
Metastatic	19%	18.2%
Deceased	n/a	7.6%***

Table 1 - Comparison of participant characteristics at baseline (n=171) and 12 months (n=86)

*Data reflects people with cancer and excludes supporters. **5% still have cancer present, 17% are still experiencing side effects. *** 7.6% of 171.

Key descriptive data were collected for each participant at baseline and reported in Table 1 above. To determine how representative the 12 month cohort of participants were to those recruited at baseline, tests for significant differences between responders and non-responders at each follow-up time-point were carried

out. No significant differences in age, cancer types, patient or supporter status, or baseline MYCaW and FACIT-SpEx scores were detected.

4.2 Evaluating the Penny Brohn Whole Person Approach for the Living Well Course

The PB-WPA model reflects the Penny Brohn Whole Person Approach (PB-WPA), which recognises the impact of cancer on the whole person (see Figure 1). The model was developed based on longstanding clinical experience within PBCC working with people with cancer, and on extensive patient reported data¹³. To determine whether the PB-WPA model was fully meeting the needs and expectations of the participants, several pieces of data were collected. The following section will report on the quality of course structure, delivery and resources to determine the level of participant satisfaction.

4.2.1 How well does the Living Well course meet participant needs and expectations?

Using an in-house evaluation form, participants rated items related to the centre, the course in general and items specific to the Living Well course sessions. The results were overwhelmingly positive (see Table 2) with only one aspect of the course, the session on financial welfare, having a mean score of 3.7/5, whereas all other aspects score over 4.0/5, demonstrating a high level of participant satisfaction.

Quality of course delivery:

Participants rated the pacing of the course as either 'just right', 'too fast' or 'too slow' (or don't know). The vast majority of participants found the pacing just right, although nearly 1/5th found the pacing too fast, and just over 1/5th didn't respond to the question. Very few participants found the course pacing too slow.

Course resources - handbooks and action plans:

Participants rated the helpfulness of the course handbook during and after the course. Handbooks were found to be extremely helpful by 91% during the course and 80% after the course. Seventy seven percent found setting the action plans helpful.

Satisfaction ratings for the National Centre resources	Mean (SD)	Satisfaction ratings for aspects of the Living Well course	Mean (SD)
The Welcome	4.7(0.53)	<i>Relaxation</i>	4.6(0.62)
Accommodation	4.9(0.35)	<i>Imagery</i>	4.4(0.74)
Food	4.6(0.58)	<i>Healthy eating</i>	4.6(0.68)
Centre staff	4.8(0.44)	<i>Nature walk</i>	4.6(0.69)
Course organisation	4.5(0.68)	<i>Stretch and breathe</i>	4.4(0.70)
Administration	4.7(0.62)	<i>Mindfulness</i>	4.4(0.78)
Course presentation	4.6(0.64)	<i>Benefits of exercise</i>	4.4(0.76)
Standard of handouts and resources	4.6(0.69)	<i>Emotional/psychological health</i>	4.4(0.73)
		<i>Financial welfare</i>	3.7(1.04)
		<i>Impact on relationships</i>	4.3(0.83)

Table 2 - Participants' level of satisfaction with different aspects of the centre and course sessions

Each item was scored out of 5, where 0 is the worst and 5 is the best.

Participants were also highly satisfied with how the course met their needs (average score 4.6/5) and expectations (average score 4.5/5). Approximately 20% of participants also wrote comments that served to emphasise their satisfaction, even when they didn't know what to expect or what they needed from the course on arrival at PBCC.

"I was apprehensive of the unknownness of being here, but it has just been amazing." Living Well course participant

Many participants went on to say that the course had exceeded their expectations, although for a few their experience was intense or overwhelming at times. Some participants felt that they wanted more time to reflect on their situation in light of new information from the course.

"The chance to share healing processes rather than always focussing on diagnosis and treatment. The course was a little intense at times." Living Well course participant

4.2.2 What are the key aspects of the course that participants found helpful?

The last data collected directly after the course asked participants to specify anything they had found particularly helpful or unhelpful on the course. Qualitative responses were received from 111 participants (65%). Overall responses were positive and five main themes were derived. These were 'sharing with others'; 'the course in general'; 'nutrition and food'; 'the doctors' talk'; 'relaxation, meditation and self-help'. Other small themes included 'staff'; 'exercise' and 'relationships'. The five main themes will now be reported in more detail below.

The course in general:

A variety of comments were received from participants that expressed how helpful the whole of the course had been, rather than one particular area. These participants found the course insightful, empowering, helpful and relevant.

"Found a little from each session very helpful." Living Well course participant

Sharing with others:

Many course participants particularly enjoyed the supportive aspect of being able to share their experiences with other participants who were open-minded or could understand the journey being travelled. Some participants found it helpful to be encouraged to speak of their own experience, others valued the sharing and found it to be supportive, providing new view-points or mutual understanding.

"I think seeing people who understand the pain and hurt around both having an illness and supporting and trying to care for someone who is ill." Living Well course participant

Nutrition and food:

Many participants found this section of the Living Well course very informative and some participants would happily have enjoyed more time on this subject.

The doctors' talk:

This aspect of the course was mentioned many times in the feedback by participants. Where explanations were given, having the science and research behind the impact of cancer on the body explained was valued and this appeared to help clients understand the value in making positive lifestyle changes.

"Explanation of the science behind things and the research done." Living Well course participant

Relaxation, meditation and self-help:

Many participants felt that this was a very helpful area of the course. Some participants explained in more detail that they now realised they could do many things to help themselves.

"I found it very helpful to learn that there were so many ways to help us on our journey." Living Well course participant

Other areas of the Living Well course that were mentioned as helpful to a lesser degree, included the staff and primarily their caring attitude to clients, the serene and calm environment, information on exercise and discussions about relationships.

4.2.3 Areas for consideration

A handful of comments relating to unhelpful aspects of the course were captured. Generally these related to the timings and intensity of the Living Well course, or wanting the total amount of information spread out over a longer period of time. There was also the desire to have more time using the facilities such as the sanctuary, the shop and to walk outside. Finally several participants mentioned that they wanted

more movement throughout the day and less sitting down for 'lengthy' sessions of discussion.

4.2.4 Determining why participants were attending a Living Well course

To understand what concerns participants had when they arrived at PBCC (and therefore whether the Living Well course was fully supporting clients' concerns), participants' concerns were collected using the MYCaW questionnaire just prior to the Living Well course. The MYCaW questionnaire was developed to allow two of the participants' most pressing concerns (relating to their cancer journey) and the severity of these concerns to be documented. Table 3 below reports the types of concerns reported for concern 1 and concern 2, indicating what clients most need support with.

	Concern 1 (n=163)	Concern 2 (n=153)
Psychological + emotional	40%	47%
Wellbeing concerns	17%	18%
Physical	19%	9%
Practical concerns	7%	16%
Supporter concerns	8%	6%
Hospital concerns	9%	4%

Table 3 - Profile of concerns for participants who arrive on the Living Well course

The categories used were reported by Polley et al. (2007)¹³.

Listing concern 2 is optional, hence not all participants filled this section in.

The top 3 types of concerns reported are highlighted in bold.

Psychological and emotional concerns were most commonly reported (40% and 47% for concern 1 and concern 2 respectively). The three most common concerns in the 'psychological and emotional concerns' supercategory, were regarding 'family problems and relationships' (29%), 'emotional problems' (17%), and 'adapting and coping' (12%).

The other sizeable supercategories included concerns about wellbeing (17% concern 1, 18% concern 2) and physical concerns (19% concern 1, 9% concern 2). For 'concerns about wellbeing', the top three concerns were 'wellbeing in general' (30%) 'nutrition' (30%), and 'exercise' (20%). For 'physical concerns', the common concerns were 'physical problems in general' (47%), 'recurrence and spread' (35%), and 'pains/aches' (10%).

4.3 Participant reported outcomes immediately after the course

To measure how well the PB-WPA model was addressing participant concerns, MYCaW scores for participants' concerns and wellbeing were analysed.

Furthermore, scores of FACIT-SpEx health related quality of life (HRQoL) were recorded and analysed to determine whether the PB-WPA model addressed participants' HRQoL.

4.3.1 Cancer related concerns and wellbeing (MYCaW)

Each participant was asked to rate how severe their concerns and their wellbeing were (0, best it could be to 6, worst it could be). Hence, a higher score indicates a more severe experience of the concern and a worse level of wellbeing.

Baseline concern scores averaged at 4.64/6 and 4.35/6 respectively, indicating that participants were experiencing these as reasonably severe. At the end of the course, an immediate statistically and clinically significant improvement in severity of concerns was demonstrated ($p < 0.000$, see Table 4 below). These mean improvements in scores were consistent with improvements in MYCaW scores from previous service evaluation¹⁴.

MYCaW scores	Statistically significant improvement?	% participants with clinically significant* improvements
Concern 1 (n=155)	✓ ($p < 0.000$)	74%
Concern 2 (n=145)	✓ ($p < 0.000$)	71.6%
Wellbeing (n=155)	✓ ($p < 0.000$)	60.1%

Table 4 - Immediate impact of Living Well course on participants' concerns and wellbeing scores from the MYCaW questionnaire

Statistical significance was set at $p=0.05$. *Clinically significant improvements are defined by any participant with an improvement of 1 point or more.

4.3.2 Health related quality of life (FACIT-SpEx)

The FACIT-SpEx questionnaire allows participants with cancer to score their total health related quality of life (referred to below as 'total HRQoL'). Total HRQoL is comprised of physical, emotional, functional, social and spiritual wellbeing subscales.

Baseline HRQoL scores showed high standard deviation (mean = 131.44, SD = 29.76, n=129) indicating a large range in the level of participants' HRQoL before the Living Well course. A subgroup of participants (n=59), were sampled with the FACIT-SpEx directly after the course, to see if immediate changes to HRQoL were initiated by the course. There was a statistically significant improvement in the mean total HRQoL score (Table 5). The emotional, functional and spiritual subscales had largest contribution to the total HRQoL score improvement. A percentage of the participants also experienced clinically significant score changes.

FACIT-SpEx	Statistically significant change?	% clinically significant changes
Total HRQoL	✓ (p<0.000)	n/a
Physical subscale	X	27.2%
Social subscale	X	23.3%
Emotional subscale	✓ (p=0.004)	42.9%
Functional subscale	✓ (p=0.001)	44.6%
Spiritual subscale	✓ (p<0.000)	n/a

Table 5 - Comparison of FACIT-SpEx scores for a subgroup of 59 participants at baseline and immediately post course

✓ = statistically significant improvement relative to baseline, X = change not statistically significant. Statistical significance was set at p=0.05. Clinically significant changes were according to Yost and Eton 2005²⁹. Data to derive clinically significant changes for the spiritual subscale has not yet been reported in the research literature, hence were not calculated for this subscale or therefore the total score.

The emotional wellbeing subscale asks participants to rate key statements including how sad they feel, how they are coping with their illness, if they worry about dying or their condition getting worse. The functional wellbeing subscale asks questions about working, enjoying life, accepting one's illness, and being content with their quality of life. Finally the spiritual wellbeing subscale asks 23 questions relating to meaning and peace in one's life, how the illness has affected one's spirituality and one's ability to feel appreciation, compassion and love for others, and about aspects of faith (see appendices for full copies of questionnaires).

5 Evaluating the impact of the experience of the Living Well course over 12 months

This section presents PROM data and participant experience data collected at 6 weeks, 3 months, 6 months and 12 months to understand in more depth, the health status of participants and the impact of the Living Well course over 12 months. Fundamentally, it is important to know whether the education and advice on healthy lifestyles, relationships and self-help techniques taught on the Living Well course continued to be utilised 12 months on. Furthermore, does the Living Well course provide the type of education and experiences that empower participants to make changes and feel able to take responsibility for their own health? Finally, it is important from a service provider's perspective to know whether participants need further support to make healthy lifestyle changes, and if so, in what form.

5.1 Health status of participants 12 months later

Table 1 showed that the treatment status of participants changed over time; after 12 months more participants had completed treatment (62.3% compared with 21.2% at baseline). A detailed breakdown of the health status of participants at 12 months is shown below in Figure 3. Whilst 19% of participants at 12 months had finished treatment and had no sign of cancer, 42% of participants with a cancer diagnosis were either still undergoing some form of treatment, still experiencing side effects, living with cancer, experiencing issues associated with metastatic disease or receiving palliative care. Hence there are still a myriad of health issues to deal with despite only 4% of the 12 month responders undergoing primary treatment at this time-point.

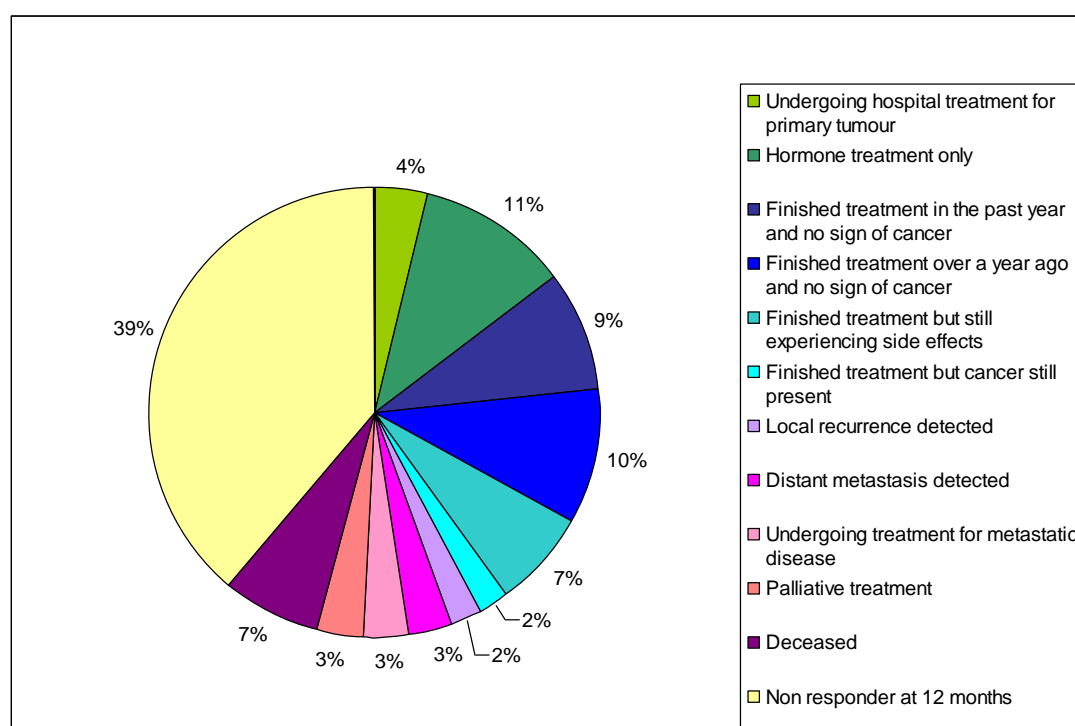


Figure 3 - State of health of participants with cancer at 12 months follow-up n=86 (excludes supporters)

5.1.1 Severity of MYCaW concerns and wellbeing through to 12 months

The severity of concerns recorded at baseline were independently rated again at each follow-up time-point to determine whether the improvement in concern scores after the Living Well course would remain or whether after time scores would gradually regress. A statistically significant improvement in mean score changes at each follow-up time-point relative to baseline was reported (Figure 4). Clinically significant improvements were experienced by between 70%-80% of participants at each follow-up time-point.

MYCaW wellbeing scores also demonstrated a small but statistically significant improvement in score after 12 months and the largest improvement was seen directly after the course. The mean wellbeing score changes are statistically significant at each follow-up time-point although the clinical effect size is not as great as with the concern scores. Clinically significant changes occurred in approximately 50% of participants at each time-point.

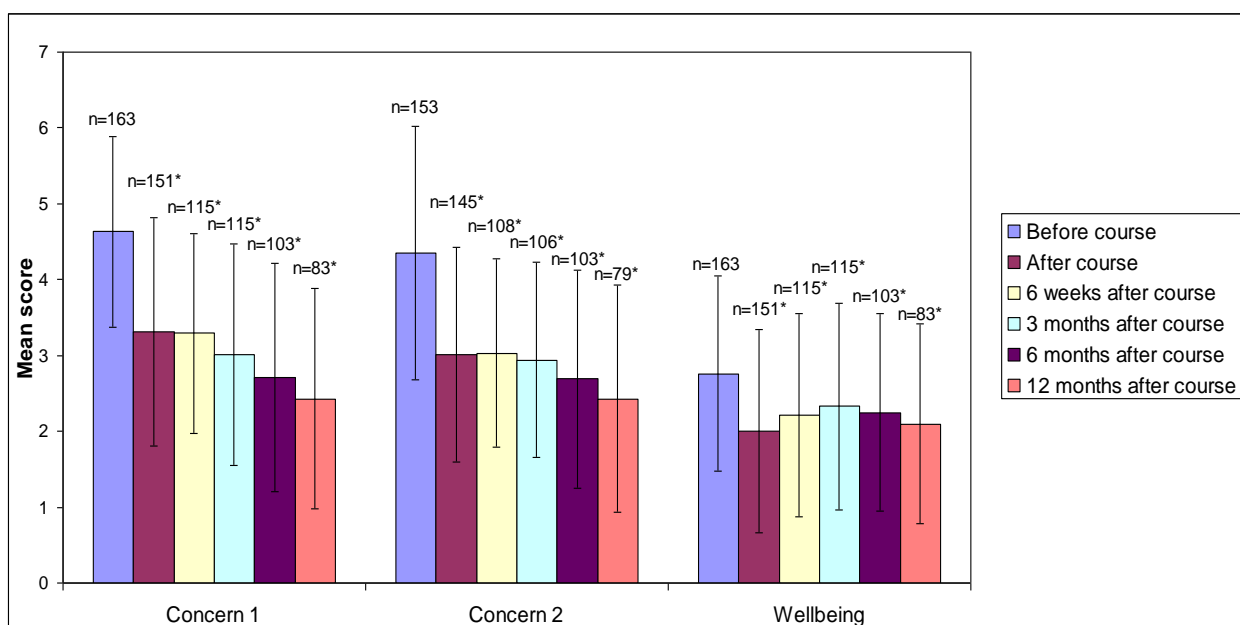


Figure 4 - Mean concern and wellbeing scores from baseline through to 12 months follow-up

The higher the score, the greater the severity of the concern or wellbeing, hence a drop in scores denotes an improvement. *Statistically significant change in mean scores compared to baseline. Statistical significance was set at $p=0.05$.

5.1.2 Health related quality of life over 12 months

The FACIT-SpEx questionnaire was used to assess HRQoL of participants with a cancer diagnosis at each time-point. The mean score changes in HRQoL scores (total score and subscales) were calculated relative to baseline over the follow-up time-points. Significant improvements over time for total HRQoL and each subscale are mapped in Table 6 below.

The results show that statistically significant mean improvements in total HRQoL present directly after the Living Well course were maintained over the 12 months, although the HRQoL at 3 months was only statistically significant for the spiritual wellbeing subscale. Once again, the emotional, functional and spiritual wellbeing subscales contribute predominantly to the improvement in total HRQoL.

Within the physical, social, emotional and functional wellbeing subscales, the percentage of participants who experienced clinically significant improvements were calculated²⁹. At 6 weeks and 3 months, clinically significant improvements were achieved by 31%-41% of participants (dependent of the subscale). At 6 months, this proportion increased to 43%-48%. At 12 months, the range of clinically significant improvements were as follows: physical wellbeing 48% (n=33); social wellbeing 31% (n=22); emotional wellbeing 51% (n=35); functional wellbeing 59% (n=41).

These data are consistent with an overall improvement in wellbeing that was also reported using the MYCaW questionnaire (Figure 4).

	Improvement in HRQoL Baseline to 6 weeks	Baseline to 3 months	Baseline to 6 months	Baseline to 12 months	Significant improvement over time?
Total HRQoL	✓ (p<0.000)	X	✓ (p<0.000)	✓ (p<0.000)	✓ (n=47)
Physical wellbeing	X	X	✓ (p=0.007)	✓ (p=0.003)	X (n=51)
Social wellbeing	X	X	✓ (p=0.02)	X	X (n=53)
Emotional wellbeing	✓ (p<0.000)	X	✓ (p<0.000)	✓ (p<0.000)	✓ (n=52)
Functional wellbeing	X	X	✓ (p=0.009)	✓ (p<0.000)	✓ (n=52)
Spiritual wellbeing	✓ (p<0.000)	✓ (p=0.01)	✓ (p=0.003)	✓ (p<0.000)	✓ (n=50)

Table 6 - Comparison of HRQoL over 12 months

✓ = statistically significant improvement in HRQoL relative to baseline, X = change not statistically significant. Statistical significance was set at p=0.05.

5.2 Do participants continue to utilise the education and self-help techniques through to 12 months?

Whilst participants were highly satisfied with all aspects of the Living Well course (Table 2), the degree to which the education translated into action was evaluated. This section will present analysis on core aspects of the Living Well course including education on appropriate exercise and food intake, the use of relaxation techniques to control stressful situations, and communicating with others close to the participants. A lifestyle questionnaire was administered at baseline and all subsequent follow-up time-points to capture the amount of physical exercise undertaken, the amounts and types of foods

eaten and the amount and type(s) of self-help or stress management techniques being utilised.

It is impossible to attribute any quantified change in lifestyle habits during the 12 month follow-up period directly to the Living Well course, as often other factors may be involved. Thus more in-depth insight into the participants' experiences of the Living Well course was also sought. At 6 weeks post course, 119 participants rated and commented upon whether they felt that the Living Well course had helped to improve their diet, levels of exercise, use of relaxation and self-help techniques or close relationships. These data will now be discussed below.

After 6 weeks, the majority of participants reported that the Living Well course had helped them to improve their diet (85.5%) and their use of self-help techniques (81.6%). Exercising and close relationships were also improved but to a lesser extent (52.9% and 53.4% respectively).

Qualitative data analysis revealed that many participants applied the information and education as a way of doing something positive for themselves.

"Lifestyle changes offer me control in a situation which can feel very beyond my control." Living Well participant

5.2.1 How do participants benefit from education on exercise?

Data was analysed to determine what levels of exercise were being attempted at baseline and whether the Living Well course had motivated people to improve their exercise.

The mean frequency of exercise was 3.4 times per week at every time-point, except 12 months where it was 3.6 times per week. See Table 7 below for more detail. Nine percent (n=15) were physically inactive at baseline. Qualitative data revealed they felt too poorly whilst having chemotherapy or weren't sure whether doing exercise would cause themselves pain after surgery.

Frequency of exercise	Baseline
None	9% (n=15)
1-2 times per week	20% (n=34)
3-5 times per week	36% (n=61)
Over 5 times per week	31% (n=53)

Table 7 - Level of exercise participants are doing when they arrive on the Living Well course (n=163)

6 weeks:

At 6 weeks after the course, 13 out of the 15 people who were inactive had been motivated enough to start exercising. Furthermore, 20% who were already exercising at baseline increased their frequency of exercise per week.

"I am doing gentle stretching now whereas before I was worried about causing pain. The cancer was diagnosed... and I experienced the worst pain I have ever felt so I had become tentative about any exercise." Living Well participant

3 months to 12 months:

Over the course of the follow-up time-points, the majority of people continued with their frequency of exercise. Some participants even reported exercising at a higher intensity level or for a longer duration, to ensure beneficial cardiovascular effects were achieved.

"I have been motivated to exercise since going on the course especially since I know how important it is to my recovery. I have increased my exercise by more than 65%." Living Well participant

At 12 months, many participants were still continuing to make improvements in the level of exercise they were doing. For some, this reflected the improved health status that accompanied completion of primary treatment e.g. experiencing fewer side-effects and fatigue.

"Because of chemo I am only now starting to slowly build up my exercise, but the course has made me realise how important it is and that it needs to be a priority, not something to just squeeze in if time allows." Living Well participant

Twenty four percent of respondents (n=21) at 12 months had also been inspired by the Living Well course to be more physically active via a group based activity such as Nordic walking. This also allowed participants to enjoy the natural world around them, as well as being part of a social network. Other activities taken up included swimming, cycling, yoga and Pilates.

"I have got on my bicycle more for short journeys and left the car at home and walked for pleasure." Living Well participant

Barriers to exercising:

At each time-point, a small proportion of participants reported a decrease in the amount of exercise they were doing before the course. Often these participants were affected by chemotherapy treatment so much that they couldn't manage exercise or were not confident to do exercise whilst having treatment.

As the health status of participants improved, they were more likely to return to work. Consequently, however, many participants then reported having less spare time for exercising. Other explanations for reduced exercise levels included the need for more support and motivation, and the bad British weather putting the participants off going outside.

5.2.2 How do participants benefit from education on healthy food intake?

Nutrition advice and education on the Living Well course is categorised as 'foods to eat in abundance', 'foods to eat in moderation' and 'foods to eat in minimal amounts'. To measure how well participants managed to improve their diet accordingly, participants recorded the number of portions of food groups they were consuming at each follow-up time-point. For each food group, the analysis focused on determining the percentage of participants who were eating the recommended amount of food items after the Living Well course and comparing this to baseline figures.

6 weeks – 3 months:

After 6 weeks, 85.5% of respondents reported that the Living Well course had helped them improve their diet. Qualitative data revealed that many participants thought the course was providing useful information to educate people as to why some foods are better to eat than others.

Quantitative analysis of the percentage of participants eating the recommended amount for each food item is shown in Table 8 below. At baseline over 90% participants were already eating the recommended amount of red meat, soya, salt and BBQ food, hence there was little room for further improvement. However, less than 30% of participants were consuming the recommended levels of refined grains (e.g. found in processed food such as cakes), vegetables and fruit, and pulses at baseline.

Participants were most likely to be successful in trying out and adhering to nutritional recommendations within the first 6 weeks - 3 months after the Living Well course. Participants reported improved levels of consumption of 12/16 and 11/16 food groups at 6 weeks and 3 months respectively.

Food item	On target at baseline (%)	On target at 6 weeks (%)	On target at 3 months (%)	Improvement at 6 weeks?	Improvement at 3 months?	improvement at 12 months?
Red meat	94	98	97	✓	✓	✓
Dairy	74	90	85	✓	✓	✓
Caffeine	65	82	78	✓	✓	✓
Damaged fats	65	83	79	✓	✓	✓
Salt	95	98	99	✓	✓	✓
BBQ food	94	97	97	✓	✓	✓
Whole grains	47	44	52	X	✓	✓
Healthy fats	69	72	65	✓	X	✓
Herbs	57	59	51	✓	X	-
Protein	52	56	45	✓	X	-
Veg and fruit	20	27	32	✓	✓	X
Refined grains	28	34	41	✓	✓	X
Processed meat	87	91	92	✓	✓	-
Alcohol	76	75	79	-	✓	X
Pulses	6	5	7	-	-	-
Soya	91	83	89	X	X	-

Table 8 - The percentage of participants on target for each food item and improvements at 6 weeks, 3 months and 12 months

'Refined grains' are those found in foods such as processed bread and cakes, 'damaged fats' are those found in processed fatty foods. ✓ indicates an improvement, x indicates deterioration and – indicates no change (0-1%) in recommended food intake compared to baseline data.

3-12 months:

After 12 months, participants reported sustained improvements in recommended levels of consumption for 8/16 food items, compared to baseline data. It was between the 3 month and 12 month time period that the challenges in sustaining the recommended diet were most likely to be experienced. If challenges were experienced, then participants tended to regress back to their lifelong habits.

Barriers to improving and sustaining healthy eating recommendations:

Open-ended questions on the participant experience questionnaire at 12 months, revealed insightful data on the challenges experienced by many participants trying to make and sustain healthy lifestyle changes. Of the 80% of participants who responded to these questions, two thirds reported challenges specifically around sustaining the dietary changes. A frequent explanation concerned the lack of support from family and friends, who didn't understand why the participants wanted to make changes and hence were not supportive of the dietary improvements.

"I feel it is very difficult trying to get family and friends to try to understand how important it is for me to eat and live as healthy as it is possible. They don't believe in special healthy eating, sometimes I feel as though they feel I am over the top in my wanting to eat healthy and sometimes scoff at my decisions. They don't believe in it making any difference to my having had cancer or trying to prevent it coming back. Yes it is very hard making changes from living on everyday foods for years..." Living Well participant

Some participants reported practical challenges such as being unable to remember all the information from the course, (often due to side-effects of treatment on their memory). Participants also reported wanting more support and resources, such as recipes or online/DVD demonstrations. Time was also a big constraint, particularly for those who had returned to work, or for participants with families to cook for as they wanted fast *and* nutritious recipes.

Some participants reported that they knew they should improve aspects of their diet, particularly alcohol, sweet foods and caffeine, but the experience of eating these foods was associated with reward or comfort and they didn't want to give up that experience.

"...I find it hard not to have a glass or 2 [of wine] most evenings and it is a real challenge to me to monitor and reduce this, it is such a pleasure and a comfort and a reward!..." Living Well participant

Finally, it was reported on many occasions that even though participants felt their healthy dietary changes gradually slipped, due to the education from the Living Well course, they became aware of this and were able to renew their efforts to make healthy improvements again.

"Found I slip back into old habits with food and drink, but overall much better than I was, and when I notice I make an effort to bring healthy habits back in..." Living Well Participant

Overall these data indicate the nutrition education from the Living Well course has a strong initial impact on the participants who attempt a range of improvements to their diet through to 3 months after the Living Well course. Furthermore some of the changes were sustained over a 12 month period. To improve the number of dietary

recommendations that are sustained long term, participants need more support from family and friends and more practical support in the form of resources and information.

5.3 How do participants benefit from education on self-help strategies?

During the Living Well course, participants were educated on the benefit of doing simple self-help techniques such as deep breathing, meditation and visualisations. Before the Living Well course, 81.2% of participants reported that they were already using a form of self-help or stress management technique.

6 weeks:

Six weeks after the course 81% of participants reported that the Living Well course had helped them improve their use of self-help techniques. This corroborated with an increase in the number of techniques being practised (see Figure 5). Qualitative data also revealed how the participants felt about the self-help techniques.

"I remind myself to relax when I get uptight and then I practise visualisation and breathing techniques. I also take more of an interest in sounds when walking in the woods, something I remember from the meditation group." Living Well participant

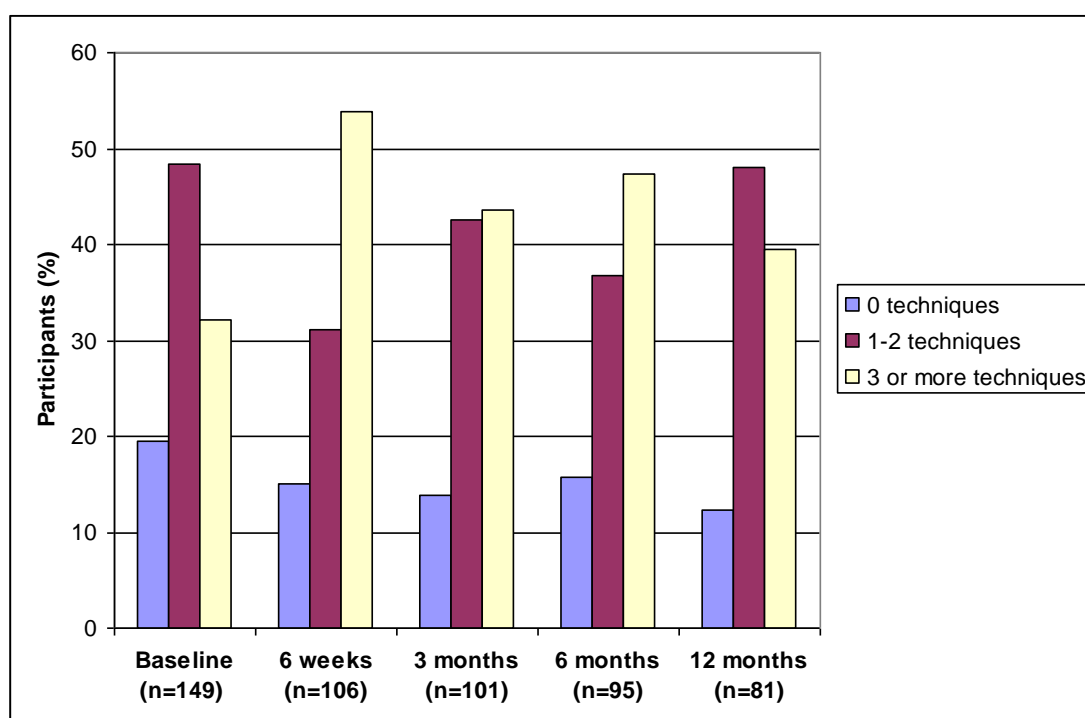


Figure 5 - Comparison of the number of different self-help techniques people are using at each follow-up time-point

3-12 months:

Twelve months after the course, 87% of participants were still using self-help techniques, 40% of whom felt that the Living Well course had directly inspired them to take up a new self-help activity and also to be realistic as to how to achieve this.

"I wanted to be able to meditate more but I have realised that concentrated short sessions are fulfilling and I use more visualisation, which is new to me, but was introduced at PB and this is amazing..." Living Well participant

Barriers to using self-help techniques:

There are a small but constant proportion of participants at each time-point who are not practising any self help techniques. The challenges to making healthy lifestyle changes were investigated at the 12 month follow-up.

Qualitative data analysis revealed that time was one of the biggest challenges to maintaining the practice of self-help techniques, especially when a participant had either returned to work or had a family to look after. The time available whilst going through treatment was no longer there.

"I do sometimes find it difficult to fit in time for meditation and relaxation into my daily routine especially when the kids are at home with me all day." Living Well participant

Having a poor memory after chemotherapy was mentioned by many participants, hence some participants needed reminding of the information on the course to use the techniques effectively.

"One of the hardest things for me is to deal with stress and put it into perspective by using the techniques learnt at the Living Well course. I did need to reinforce the techniques from the course recently as I started to forget them. I think this is because I was still in chemo when I attended the Living Well course and my brain was not functioning properly ... I feel recently reinforcing the techniques have helped me to keep on track...and not go back to my stressed pre-illness life." Living Well participant

5.4 Impact of the Living Well course on relationships

The Living Well course asks clients to think about the impact that cancer has had on their relationships, for example, a sense of being viewed differently by others or a change in interactions and connections with loved ones. The course encourages open and honest communication with friends and family, as well as work colleagues and healthcare professionals such as nurses, GPs and oncologists.

The impact of the Living Well course on participants' close relationships was investigated using open-ended questions at the 6 week and 12 month time-points.

After 6 weeks, 53% of participants felt that the Living Well course had helped improve their close relationships. Qualitative data regarding the state of participants' relationships showed an overwhelmingly positive and often deep effect for individuals. Some participants felt that their close relationships were good before attending the Living Well course. Forty-two participants (35%), expressed how the Living Well course had helped them to talk more openly with family members about their situation and to express their emotions rather than keeping these to themselves. Furthermore, they recognised the value of their relationships more after attending the course.

*"I have shared the things I learnt with my daughter, father and close friends to give them hope and help them to understand what I need to do to create a positive environment".
Living Well Participant*

Several participants also commented on how their communication with and handling of their children had improved.

“...My relationship with my children has been helped as my learning from the course has helped me to deal with my stress and tiredness and therefore made me be able to spend long periods of time with them [children] without snapping or being grumpy.” Living Well Participant

Barriers to improved relationships:

A few participants felt that their relationships had not improved as a result of attending the Living Well course. Reasons identified from the qualitative participant data revealed that for some, after attending the course, they understood what was important to themselves, which influenced further decisions around close relationships.

A few participants still felt frustrated and unsatisfied with their relationships. Two reasons were identified here, which were ‘being taken for granted’ and the supporter having not shared the Living Well course experience. This second reason appeared to set up conflict in participants who then wanted to talk more openly but couldn’t get their needs heard.

6 Understanding the wider impact of the Living Well course

The previous section reported on the specific impact of core components of the Living Well course. This section will report on the wider effects which have been identified from the service evaluation data, including the effect on supporters, patients with metastatic disease, interactions with health professionals and being able to take responsibility for one's health.

6.1 The impact of the Living Well course on the supporters

This section will present findings specifically about the concerns, needs and wellbeing of supporters (n=36, 21%) who attended the course. It will also describe in what ways they feel they benefited from the Living Well course.

6.1.1 Supporter concerns (MYCaW)

Data from the MYCaW questionnaire showed that supporters' concerns often relate to different areas than those of the person with cancer (Figure 6). The most commonly reported concerns were psychological and emotional concerns (38%). Within this supercategory the three main concerns were 'family problems and relationships', 'emotional problems' and 'psychological issues'. Supporter specific concerns (34%) related to 'physical health of the patient', 'concerns over providing support' and 'mental health of the patient'. Practical concerns (11%) were either 'financial' or 'work related'.

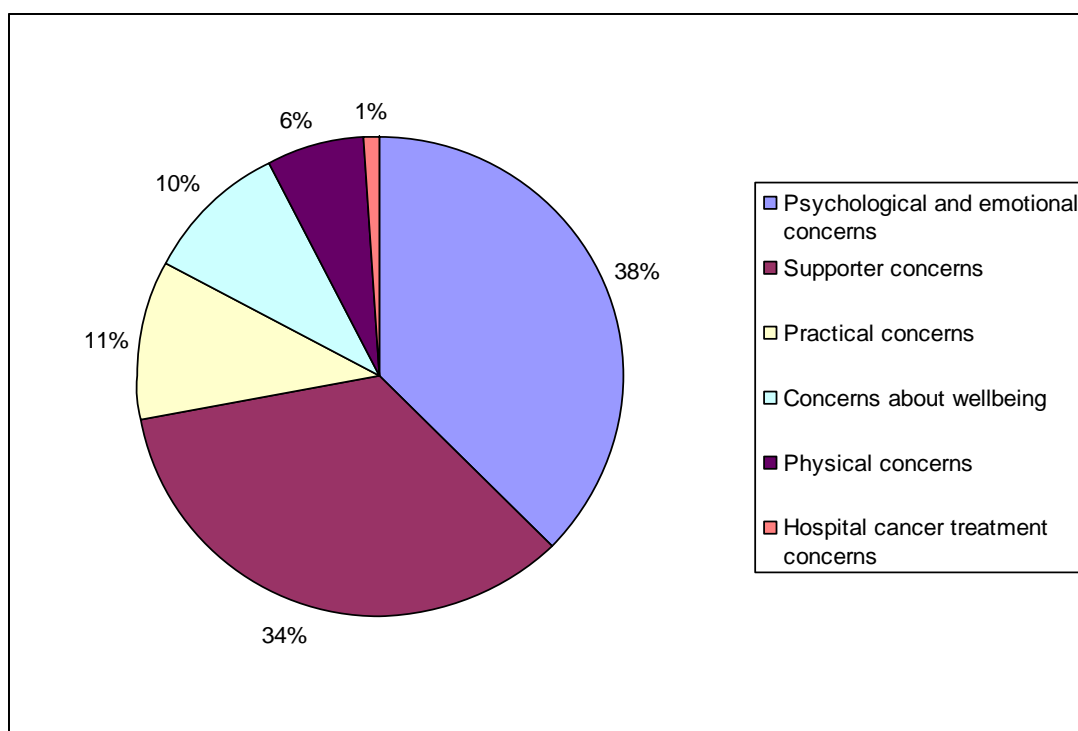


Figure 6 - Supporter specific concerns at baseline

MYCaW concern and wellbeing scores were reported at baseline and followed up at each time-point. At baseline, the average severity of concerns 1 and 2 were 4.25/6 and 4.1/6 respectively. The change in concern scores were statistically significantly improved at each follow-up time-point relative to baseline and showed a very similar profile to the whole group scores (Figure 4).

Mean wellbeing scores at baseline were 2.8/6 which was not as severe as the whole group. There was a significant improvement in wellbeing directly post course and a trend for improvement at each follow-up time-point. A bigger number of supporters would improve the power to detect a statistically significant improvement.

6.1.2 HRQoL of supporters

The HRQoL of the supporters was not captured as the FACIT-SpEx questionnaire is not aimed at this group, rather it is written for a person with a cancer diagnosis. For the participants who attended with a supporter, however, they reported significantly higher social wellbeing immediately after the course and at 6 weeks after the course. As the number of respondents dropped at each subsequent follow-up time-point, further analysis was not done as it would not have been meaningful.

6.1.3 Supporter experience of the Living Well course

Qualitative data from supporters was gathered at 6 weeks and 12 months to understand their experience of the Living Well course in more detail.

Mutual benefits were experienced by the supporter and by the participants who brought the supporter. For many supporters the Living Well course emphasised that their own wellbeing was important, and gave them the chance to have time for themselves and relax whilst the patient was being cared for by PBCC. From the patients' perspective, the most common comments were that they were glad the supporter was getting time to talk with other supporters who understood the experience they were going through. This appeared to ease the worries that the patients had about their supporter's wellbeing and facilitate more communication.

"Many people on the course who had the disease themselves, said they thought it was far harder for family and carers to deal with, than the person with cancer. So I found myself amongst friends. Also my partner was cared for and I found I could relax a bit and concentrate more on my own needs. The staff made this clear, I was there for myself. I got wonderful inspiration, ideas and new contacts." Living Well participant (supporter)

"I was extremely grateful they came on the course with me... They benefited from being able to talk freely with other course members, share experiences and fears. I was extremely pleased to see them interact with the others during the breaks – it did them a lot of good which in turn greatly gladdened me." Living Well participant (patient)

6 weeks -12 months:

Many participants reported that as a dyad (patient and supporter) they had closer relationships and more open communication about the cancer journey, as opposed to keeping their fears from each other.

Reasons identified from the qualitative data that contributed to the improved dyad included the supporter feeling more informed about the cancer from the patient's perspective, and being more aware of how to support the cancer patient in a constructive way. Furthermore for some supporters, the course gave them the opportunity to accept the diagnosis and regain their own sense of wellbeing.

"As a supporter you need all the help you can get to 'support in the right way' and Penny Brohn offers that. Also what is beneficial health wise for the cancer patient is also good for the supporter, who will have to learn to deal with raised stress levels." Living Well participant (supporter)

From the patients' perspective, the supporters' increased awareness of the effects of the cancer and how to constructively support, meant that the supporter was more proactive at home. This is where the support is crucial, once the course has finished. Finally, supporters were asked if they would recommend this course to other people who are supporting someone with cancer, to which all respondents replied 'Yes'.

6.2 Impact of the course on patients with metastatic disease

Although this was not a primary aim of the service evaluation, data from the 19% of participants (n=26) who reported having metastatic disease at baseline were analysed to provide a more detailed understanding of the needs and experiences of this group of clients. The majority of this group had returned for more support from PBCC over the 12 months after the Living Well course.

The types of concerns reported at baseline by the participants with metastatic disease were in line with those reported by the whole cohort (see Table 3), with the most commonly reported concerns being psychological and emotional, wellbeing concerns and physical concerns. MYCaW concern 1 and 2 scores and wellbeing scores were similar to the whole cohort at baseline (4.83, 4.43 and 2.92 respectively) and similar improvements in the concern and wellbeing scores were reported.

HRQoL data were analysed to understand how having metastatic disease impacted on these participants' scores. Total HRQoL scores were not significantly different at baseline in comparison to participants without metastatic disease (excludes supporters). However the physical wellbeing score at baseline for participants with metastatic disease was significantly lower than participants without metastasis (p=0.004). There were no significant differences on other subscales at baseline.

At 12 months, there were only 9 people who responded who had metastatic disease at baseline, thus the data reported below is not representative of the whole group of people with metastatic disease. Interestingly, however, in comparison to participants with a primary cancer diagnosis, the metastatic group of people reported a greater improvement in their total HRQoL from baseline to 12 months ($p=0.039$), and on the social wellbeing ($p=0.039$), emotional wellbeing ($p=0.038$) and spiritual wellbeing subscales ($p=0.018$).

These data indicate that further evaluation with a larger group of clients with metastatic disease is needed to confirm the benefit that people with metastasis gained through coming on the Living Well course.

6.3 Understanding the impact of returning to PBCC after the Living Well course

Fifty three percent of participants, comprising supporters and patients, returned to attend more courses at PBCC or individual therapy sessions. Data for this group was analysed to provide more information on the specific needs of this client group.

On average, participants returned 4 times in the 12 months following the Living Well course. The types of concerns reported at baseline by the participants who returned to PBCC were very similar to the whole group (Table 3) except there were a greater number of psychological concerns reported.

The quantitative PROM data was thus further analysed, to determine whether there were any differences in the MYCaW scores or HRQoL scores at baseline or at follow-up between participants who did and did not return for further support from PBCC. At baseline, participants who returned to PBCC scored their MYCaW concerns more severely (statistically significant $p=0.04$) and had worse average HRQoL although this was not statistically significant.

When analysing 12 month follow-up scores, returning participants tended to have a greater improvement in their MYCaW concern 1 ($p=0.011$) and concern 2 ($p=0.002$) scores. There was also a much better level of improvement in the HRQoL scores of the 'returners' ($p=0.007$).

Participants returning to PBCC, therefore, were more likely to be in need of a greater degree of support. These participants also made greater progress in attaining better HRQoL and reducing their concerns, compared to participants who didn't return to PBCC.

To determine clinically significant improvements in HRQoL, the degree of change in HRQoL was analysed. Participants who returned to PBCC were nearly twice as likely to experience an extreme increase in their HRQoL compared to non-returners (38% vs 19%), with an extreme increase likely to reflect a clinically significant change (see Figure 7 below).

Further analysis of the qualitative data at 12 months revealed that the impact of returning to PBCC for more support was extremely valuable to many participants to reinforce the education gained on the Living Well course and to seek clarification on information once they had had the chance to try making lifestyle changes. Other participants felt they needed more support from key members of staff, to maintain the healthy lifestyle changes that had been recommended.

"I seem to fall back into old habits and require a return to PB to keep me on track (every 6 months)..." Living Well Participant

"After my second visit I have a clearer understanding and now my family eats the Penny Brohn healthy plate..." Living Well Participant

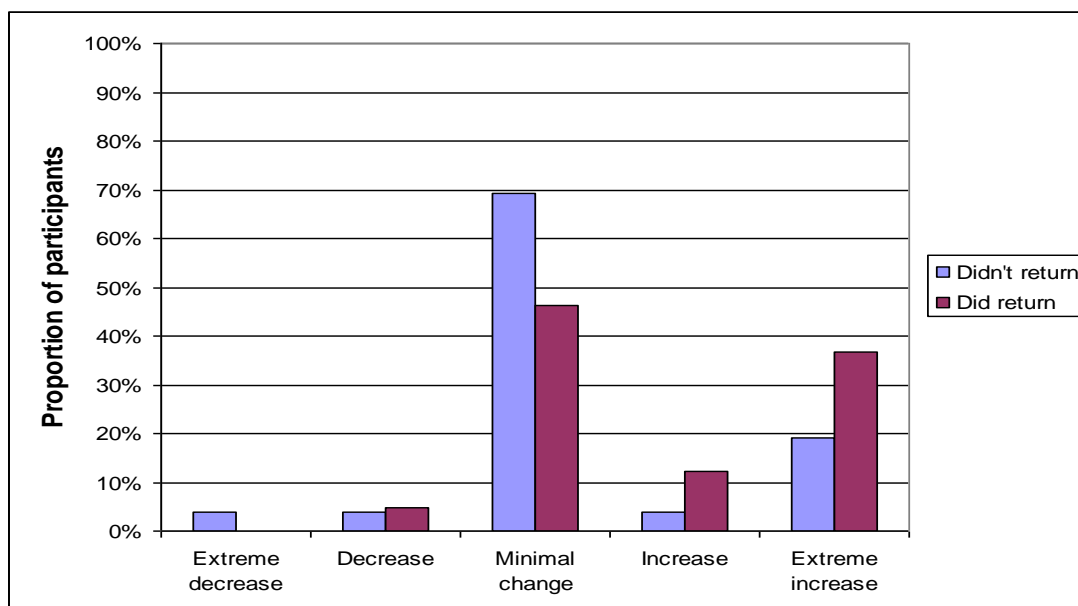


Figure 7 - Changes in HRQoL at 12 months (relative to baseline) for returners and non-returners to PBCC after the Living Well course

Returns n=41, non returners n=26. Extreme increase category is likely to reflect participants who had clinically significant changes.

6.4 The impact of the Living Well course on access to medical services

Participants were asked after 12 months if the Living Well course had made a difference in how they accessed medical services. Fifty three percent of the 12 months cohort responded.

The most commonly reported theme was having more confidence and assertiveness when talking to healthcare professionals and actually asking for the help they needed. Participants noted that they were more specific in their requests for help, such as being referred for psychological support and also requesting Vitamin D tests through their GP.

"The course gave me the confidence to seek help from my GP and Clinical Nurse Specialist with any concerns rather than 'suffering in silence'..." Living Well participant

Some participants also spoke of disclosing more readily to their GP and oncologists about the use of complementary therapy support, preparing for consultations beforehand, as well as requesting to be copied in to medical correspondence.

"I have made myself more informed about holistic approaches and spoken to my GP/consultant about this." Living Well participant

The increased confidence appears to stem from the education received on the course regarding cancer as a disease and the benefits of self-care and living a healthy lifestyle. Furthermore, many participants left the course with an appreciation of the boundary

between what the NHS can and cannot provide and what is down to the individual to be responsible for. This data indicates that some participants have made a transition to taking responsibility for their own long-term health, rather than relying solely on medical services.

"I've been more confident in how I have dealt with my illness and feel that taking responsibility for my wellness has enabled me to speak to professionals about what I want. My attendance on the course was a real education for which I am very grateful." Living Well participant

The final theme noted in the data was the lack of emotional support, experienced in the NHS care pathway as well as a lack of understanding about the impact of cancer on the whole person, and the patient experience.

"I feel perhaps GPs don't understand quite how devastating being told you have cancer is and often after there isn't much help in sorting out our feelings and experience." Living Well participant

6.5 Impact of the Living Well course on seeking out own community and charity based support

Seventy six percent of participants at 12 months were motivated to take up a new activity, the majority of which were community based groups (e.g. tai-chi, Women's Institute, choir, art group, sewing) and a quarter of these were exercise related (e.g. Zumba, yoga, Nordic walking group). Twenty five participants (35%) responding at 12 months had also visited other centres typically providing counselling, complementary therapies and meditation. A further four participants had gone on to access psychological support through the NHS.

7 The on-going needs of participants after the Living Well course

To inform PBCC of how to best support their clients and to understand what else was influencing participants' health over the course of the year, participants reported any new concerns they had and what other things participants felt were affecting their health at each follow-up time-point. At 12 months, participants were also given the opportunity to comment on any other effect that the Living Well course had had on them, which hadn't already been covered in the questionnaires.

7.1 Understanding participants' on-going concerns

Approximately 50% of respondents reported new concerns at each follow-up time-point. Psychological and emotional concerns were the predominant type of concern when participants arrived on the course. Whilst there was a 50% reduction in this supercategory at 6 weeks, the frequency of these concerns gradually increased through to 6 months. Many of the concerns for this supercategory were around 'family and relationships', 'fear and anxiety', 'adapting and coping' and 'the future'.

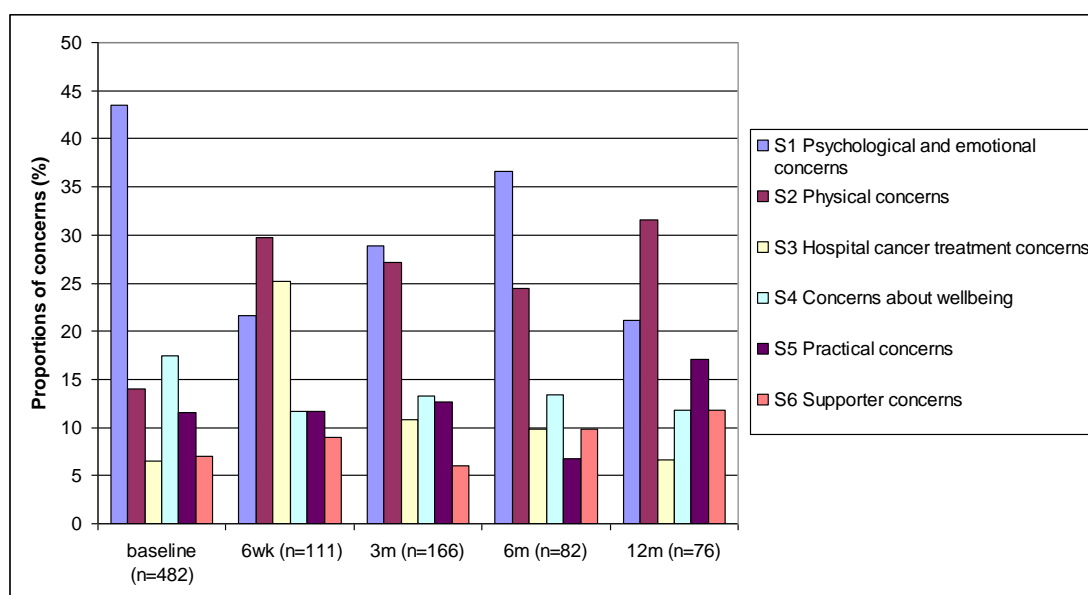


Figure 8 - Comparison of types of new concerns that participants experienced at each follow-up time-point, relative to baseline

Each participant could state up to two new concerns. The n values represent the total number of concerns stated, rather than the number of participants responding.

The proportion of physical concerns doubled at 6 weeks through to 12 months. The most common physical concerns at every time-point were related to 'recurrence and spread'. Other frequently reported concerns were 'poor energy', 'pain and aches' and 'physical problems'.

Finally, the proportion of concerns about hospital cancer treatment peaked at 6 weeks then dropped back down from 3 months to 12 months. These concerns all centred around the hospital treatment and its side effects.

There was very little variation in the proportions of practical, supporter or wellbeing concerns throughout the year. Concerns around wellbeing at each time-point were related to 'general wellbeing', 'nutrition' and 'exercise'. Practical concerns related to 'work' and 'finances', and supporter concerns related to the 'physical health of the patient' and the 'psychological health of the supporter'.

7.2 What other important things were affecting participants' health?

This response on the questionnaire is not compulsory, however, between 53% and 63% of respondents at each time-point had something important to report. These data were coded as previously reported¹³. Approximately 30% of participants reported an 'Improved awareness of own wellbeing' which reflects any improvements in lifestyle through being more relaxed, getting less stressed, changing priorities and letting go of negative habits. The 'negative impact of cancer' was also frequently reported (approximately 25% of participants), and includes comments relating to pain, aches, lymphodema or discomfort from hospital treatment for cancer. It also encompasses anxiety, fear, worry at length of recovery time or a diagnosis of metastasis. It also includes negative comments about medical staff being unprofessional or overly pessimistic.

The data from section 7.1 and 7.2 and Figure 3, clearly correlate to reveal that some 25% of participants are still being very affected by the negative impact of cancer and its treatment. On a positive note, the qualitative data also revealed that about 25% of participants considered the living of a healthier lifestyle something that was positive, important and affecting their health for the better.

7.3 Understanding what type of on-going support participants want

A theme developed from the qualitative data of participants wanting more support, resources and practical suggestions to help them maintain the healthy changes they were making. Overall, participants wanted a range of ongoing support, the most common including newsletters; access to a facilitator or doctor at PBCC after the course as and when they needed support; more contact/reunions with the other clients attending their particular course; prompts via email about healthy eating.

By far the most frequent type of support requested was actually to have a PBCC centre on their doorstep as for many participants, travelling to Bristol was very tiring and not always feasible.

"Just sorry I couldn't bring my mum to further courses as the journey was too tiring. Hope that one day there will be centres in many cities." Living Well participant

8 Discussion

The aim of the Living Well service evaluation was to measure the levels and areas of benefit from the Living Well course and to understand the client experience. The rationale behind this was to provide PBCC with information on whether the Living Well course is best meeting the needs of the participants and to identify whether any aspects of service provision could be improved.

8.1 The importance of evaluating the 'whole person'

The tools and methods used were designed to quantify participant satisfaction, to measure outcomes using PROMs, and to capture the 'lived experience' of the participants utilising advice from the Living Well course, all over the period of 12 months. Bespoke participant experience questionnaires were designed for use at 6 weeks and 12 months after the Living Well course to capture any data on the wider impact of a cancer diagnosis and the support offered by PBCC, which may not be captured by the PROMs. Furthermore, it is well established that sustaining healthy lifestyle changes in populations with chronic conditions such as cancer can be challenging and can require a lot of resource and support^{30,31,32}. The qualitative approach therefore enabled data specifically relating to participants' experiences of making healthy lifestyle changes to be recorded.

The learning gained from the combined data analysis will now be discussed in two sections, 'empowering change' and 'changes to wellbeing', to enable PBCC to understand from the clients' perspective, why the Living Well course is beneficial. For the service provider it is also important to understand from the clients' perspective, whether there are further areas that PBCC needs to address to maximise the short and long-term effects of the Living Well course, to support the minority of participants who did not have significant improvements after attending. This will be discussed under 'barriers to change'. Finally the limitations of the service evaluation will be discussed.

8.2 Empowering change

8.2.1 The Penny Brohn Whole Person Approach and the Living Well course

The development of the PB-WPA was in response to the recommendations of the NCSI that the whole person should be catered for¹, and was designed to be person-centred and flexible to cater for the large range of clients who visit PBCC (see Table 1). The PB-WPA model content was informed by previous service evaluation data^{13,14} from nearly 800 clients at PBCC and The Havens (formally Breast Cancer Haven) and 30 years of in-house experience of supporting people with cancer. This resultant aim was to provide a Living Well course, based on a model that supports clients, by giving them knowledge, support and tools to make beneficial lifestyle changes.

Participants reported extremely high levels of satisfaction with nearly every aspect of the content and delivery of the Living Well course (see Table 2) and the Living Well course often exceeded their expectations. Moreover, thematic analysis of the participant experience data (6 week and 12 month follow-up), revealed that a proportion of participants were proactively taking responsibility for their own health and had a more realistic view of what the medical services in the NHS could and could not offer. These participants were typically accessing further community and charity

based groups and resources, and were continuing with healthy lifestyle changes regarding nutrition, exercise and self-help techniques. Combined with the patient satisfaction data, this demonstrates that the Living Well course is translating into immediate improvements in the majority of participants' HRQoL.

8.2.2 The key components to empowering change

Several key aspects of the Living Well course will now be discussed, which were identified by participants as helpful and appear to be underpin participants' positive experiences.

The Penny Brohn Whole Person Approach:

The PB-WPA treated the participants as people, not just as a cancer diagnosis. There was also something of relevance for everyone on the Living Well course, irrespective of the stage of the cancer journey, or whether participants were supporters. Because an important component of the course was experiencing self-help techniques, participants came away with lots of new things to try that they knew were beneficial. Participants reported that this gave them a sense of control over their life, which is often lost due to the devastating impact of diagnosis and the speed at which treatment begins after diagnosis.

Sharing:

A core principle of the Living Well course is allowing participants to share their stories. The benefits of sharing narratives are well documented^{33,34}. Participants not only valued this time to speak of their own experience, but were sometimes inspired by how other participants were coping with their diagnosis or the activities they were doing. The sharing also gave participants the chance to swap successful strategies and advice. This sharing aspect was also particularly important for supporters of people with cancer, as there is often less attention given to needs of supporters of people with cancer.

Education:

Many participants arrived not knowing much about cancer as a disease or how it affects their body. Thus the talk by the medical doctors gave them new insights into the disease and helped them to understand from a scientific perspective why it is important to make the healthy lifestyle changes recommended. To further reinforce this new knowledge were specific sessions on nutrition, exercise and using self-help techniques, which were identified as helpful. The combination of these four sessions appears to have given participants the 'how and why' knowledge required to then implement healthy changes, by explaining and educating as opposed to just telling them what they should do. Hence the Living Well course was a very educational experience and participants began to understand how the healthy lifestyle recommendations could help support their mind and body. For example, recent meta-analysis evidence has highlighted the beneficial effect of exercise at all stages of the cancer journey^{16,35}. Furthermore, patients who learn about the positive benefits of exercise whilst undergoing treatment are more likely to be physically active 5 years later³⁶. Some participants, however, were confused as to when it was OK to exercise, particularly if they were feeling any pains (a common side effect of cancer treatment), as their instinctive action was to avoid exercise.

The education from the Living Well course also had wider effects on other aspects of the participants' lives. Communication, for instance, was often reported as improved with loved ones and with medical practitioners. In the case of close family members, participants felt more able to talk openly about their experience and feelings and in turn this helped the people around them understand issues and in some cases be more supportive. Many participants came away with more confidence in talking to medical practitioners about their support needs, and feeling that they were getting more out of their medical consultations. This was primarily because they understood more about cancer as a disease but sometimes they prepared for the medical consultation or asked to be copied into medical correspondence. PBCC's philosophy is one of integrated care and working alongside other healthcare providers, yet disclosure of complementary medicine use by patients is an issue throughout the NHS³⁷. After the Living Well course, many participants had more confidence to discuss complementary medicine with the medical practitioners because they understood how it could benefit them.

8.2.3 Changes to wellbeing

The PROMs revealed statistically and clinically significant mean improvements in the specific concerns that many participants reported (using MYCaW; Table 4). There were also statistically significant mean improvements in health related quality of life (HRQoL) for participants with a cancer diagnosis (measured with FACIT-SpEX; Table 6), of which a proportion of HRQoL improvements (31-59%) were also clinically significant. The areas of wellbeing that most improved were the spiritual, emotional and functional wellbeing. These aspects of HRQoL were significantly improved directly after the course and were most likely to remain significantly improved over the 12 month time period.

Psychological and emotional wellbeing:

The 'psychological' and 'emotional' impact of cancer are two prongs on the PB-WPA model. They were the most frequently reported area of concern (using MYCaW) for participants at baseline and also featured prominently at most follow-up time-points. The improvements in MYCaW concerns were echoed with the FACIT-SpEX tool, as the emotional wellbeing domain was statistically significantly improved directly after the course and at every follow-up time-point except 3 months.

Spiritual wellbeing:

The spiritual wellbeing subscale was deliberately incorporated into this service evaluation as one of the key components of the PB-WPA model is the 'spiritual' impact of cancer. Spiritual wellbeing relates to the overall experience of meaning and peace in one's life. This may or may not be attributed to religious faith. This correlates with many statements participants reported around feeling calmer, and more at peace with their situation directly after attending the Living Well course. Whilst very few participants identified initial concerns in the spiritual wellbeing domain at baseline, statistically significant improvements were seen at every follow-up time-point. The spiritual wellbeing domain is also least likely to be catered for via the NHS care pathway and potentially the Living Well course is catering for a need that has not been clearly recognised. More recent evidence has started to show a correlation between level of spiritual wellbeing and overall wellbeing^{38,39,40,41}.

Supporters:

The role of the supporter had not previously been evaluated within PBCC although supporters have been encouraged to attend Living Well courses since their inception in 2008. As there were 36 supporters recruited into the evaluation, data for this group of participants were analysed and profiled as a separate group.

Published evidence highlights just how severe the impact of a cancer diagnosis is on the supporter or carer^{42,43,44} and underlines the importance of including the close family in supporting a person with cancer^{45,46}. Cognitive-based interventions have the potential for reducing emotional distress in the patient-carer dyad⁴⁷. As PBCC's National Centre is set up to provide night care for people with cancer, from trained nurses, the supporter benefitted from 'time-off' from their role and being able to share their experiences with other supporters. The participant with cancer felt happier, knowing their supporter was getting time and attention for themselves and a win-win situation was created. Supporters also learnt about cancer and the reasons why lifestyle changes were important, and reported leaving as a more 'effective' supporter, as well as with more awareness of how to look after themselves. A few supporters also described how attending the course helped them to come to terms with the cancer diagnosis.

There is the potential for prevention of disease and improved wellbeing in this group of participants and the benefit of the Living Well course for supporters of people with cancer cannot be underestimated^{48,49,50,51,52}. Supporters were asked directly if they would recommend the Living Well course to other supporters, and gave a resounding 'Yes'.

Metastatic participants:

Participants with metastasis were a small group within this service evaluation who came with similar concerns and HRQoL levels to the participants without metastasis. There were two striking findings from the data, but as the numbers are so small these data must be interpreted with caution, but do make the point that more evaluation of the effect of the Living Well course for clients with metastasis should be undertaken. At baseline these participants had much worse physical wellbeing, but at 12 months follow-up, changes in their total HRQoL, emotional, social and spiritual wellbeing was significantly better than the participants who had a primary cancer diagnosis. The improvements may reflect the fact that the majority of participants returned for more support from PBCC.

Participants who returned to PBCC:

Ninety participants returned to PBCC an average of 4 times over the course of the 12 month follow-up. Support became a prominent theme in the qualitative data, whether it was participants who didn't have enough support, were finding support in their locale or returned to PBCC for more support. If participants returned to PBCC, they often also commented on the benefit of clarifying information and advice, and on the help with maintaining lifestyle changes that were starting to slip away. Thus to determine if more support from PBCC had any quantifiable effect, the degree of HRQoL changes from baseline to 12 months specifically for returning participants (n=41) was analysed (Figure 7). Participants who returned either to attend another course or individual therapy sessions at PBCC, were twice as likely to achieve what are likely to be clinically significant HRQoL changes at 12 months.

This preliminary finding indicates that providing more support from PBCC over the 12 month period after the Living Well course is likely to improve client outcomes. Furthermore, many participants who couldn't make it back to PBCC reported that in an ideal world they wanted more PBCC style support in their local area, where they could drop in 'as and when' they wanted to.

8.3 Barriers to change

The challenges experienced in making healthy lifestyle changes (diet, exercise and self help techniques) and utilising the techniques taught, were identified from the qualitative data. Participants most frequently reported that the crucial time in which positive changes started to slip was from 3 months onwards.

The most frequently reported difficulties were with nutritional improvements. Data at 6 weeks and 3 months shows that participants were motivated to try improving their diet and reported a much better awareness of what a healthy diet consists of. Unfortunately many extrinsic barriers to improving diet were reported, (which had nothing to do with the Living Well course). One frequently reported barrier was the lack of support from friends and family. This comprised other members of the household who didn't want to eat healthier food hence the participants cooked separate meals; the participants being mocked for trying to be healthy as the family/friends didn't believe that there was any link between they type of food eaten and cancer incidence; and socialising often incorporated drinking alcohol and eating unhealthy foods. Due to the increased awareness of healthy eating, this type of socialising was not always enjoyed by the participants, but they still want to be part of their social circle. Thus for many, integrating the lifestyle changes into the wider circle of family and friends became difficult and led to participants struggling to maintain improvements.

Participants on the Living Well course who were undergoing treatment for cancer often found that their memory and ability to process information was poor. Despite the notes and the handbook, they were confused about nutrition advice and needed clarification, otherwise were likely to revert back to previous eating habits.

In the case of exercise, participants were likely to become sedentary due to side-effects of cancer treatment such as fatigue and pain. This group of participants may benefit the most by having more support from PBCC over the first few months after the Living Well course.

The final frequently reported theme related to lifestyle improvements was work-life balance and time. During the treatment and recovery phase when participants were not working, they had plenty of time to try out new recipes, self-help techniques and do more exercise. However at the point of returning to work, when the amount of available time suddenly decreased, the ability to integrate a new level of exercise, relaxation and improved nutrition was very difficult. This was even harder if the participant had children to care for. Thus balancing the demands of caring for oneself, one's family and fulfilling work commitments (often with subclinical cognitive side-effects) is an on-going issue for many participants. The 'return to work' period may be an important time when more support from PBCC would be beneficial to the client.

Other less frequently reported barriers which may be harder to control, included being put off exercise by the bad weather, associating eating food with comfort, reward and

pleasure, and actually just not liking some of the healthier food. One final point reported on a few occasions was the lack of incentive to maintain change once they found out the cancer had gone, hence the idea of preventing recurrence was missed.

8.4 Limitations of the service evaluation

This service evaluation was designed solely to evaluate the participants' experience of the Living Well course, not to compare the effectiveness of the course to any other type of treatment that participants received. Hence the results are not generalisable outside of PBCC.

The participant response rate at 12 months was 50%, which considering the severity of illness of some participants is good. When comparing the profile of respondents at 12 months (see Figure 3 for the range of health states) to the whole group at baseline, there were very few significant differences in participant characteristics. However it is possible the non-responders had less positive experiences and that the group at 12 months captured more of the positive elements of the participants' experience. The tools used were designed to get a snapshot of the 'whole picture', rather than a detailed analysis of every section of the Living Well course as this would have caused questionnaire fatigue in the respondents and decreased the response rate. Furthermore, recall bias on the part of the respondents may have affected the accuracy of the reporting of lifestyle changes, this is particularly known to be the case for nutrition recall^{53,54}.

This service evaluation did not assess the economic impact of the courses, although under the reformed NHS structure, it is acknowledged economic data is increasingly important. Whilst no final statement on economic benefit can be made, it is worth considering the potential economic impact. Many participants experienced improvements in concerns, lifestyle and HRQoL, and reported taking responsibility for their own health. Thus the potential for reducing recurrence of cancer and improving other chronic comorbidities is present e.g. cardiovascular diseases, obesity and diabetes. Where participants were accessing other community and charity based resources, they were improving their support mechanisms and being less socially isolated which is beneficial to HRQoL. Finally the benefit derived by the supporters should not be underestimated. Whilst the supporter provides a lot of patient-centred care for the patient, the negative impact on their own health is great^{42,43,44}, thus supporters are more likely to have serious disease themselves, be depressed and consequently be needing a lot of support from the NHS. Educating a supporter on how to look after themselves is a preventative step which may have economic benefits as well.

8.5 Using this service evaluation for commissioning the Living Well course

A multitude of reports over the last two years have called for models of behaviour change that empower a person to be effective and proactive in taking responsibility for their health^{3,4,5,6}. Moreover, a shift towards collaborative healthcare practice has been recommended. Further, for PBCC's services to be eligible for commissioning within the NHS, they must have a set of specific and measurable objectives.

The PB-WPA and Living Well course incorporates familial, social, and economic aspects of a person's life, and takes a collaborative and integrated approach to healthcare provision. This service evaluation has demonstrated that the Living Well course successfully encouraged proactive support and self-management. A focus on behaviour change translated into clinically significant improvements in participant reported concerns and wellbeing (50-81% of participants), and HRQoL (31-59% of participants), hence course impact is measurable. Positive and useful strategies to maximise behaviour changes in people with a cancer diagnosis and their supporters have also been identified which will inform service development at PBCC.

9 Conclusion

The aim of the service evaluation was to measure the benefit that participants were receiving from the Living Well course and identify areas that could inform current and future service provision at PBCC. The PB-WPA was designed to support the 'whole person' and the Living Well course was intended to meet the needs of people with cancer, as identified by the NCSI¹.

The combined results of the Living Well service evaluation have demonstrated, very clearly at times, that participants were highly satisfied with the course and that the immediate benefit of attending was measurable, in terms of improved HRQoL and improved MYCaW concerns and wellbeing.

The combination of specific units of 'education and explanation' about cancer and why healthy lifestyle changes are beneficial, alongside input from medical doctors and the opportunity to share experiences with other participants, were identified as the most helpful aspects of the course. The Living Well course experience enabled the majority of participants to regain control over aspects of their life and start to take responsibility for their health. For some, this empowerment led to long-term improvements in exercise, food consumption, use of self-help techniques and the ability to communicate with family, friends and medical professionals. These improvements were reflected in the 12 month outcome data, where a sustained improvement in HRQoL and MYCaW concerns were reported.

PROMs are limited in what they can measure, thus qualitative data was also collected to ensure that participants had full opportunity to share their experiences (good or bad) of the Living Well course, and the subsequent experiences of applying the education and techniques. A picture emerged that confirmed the extrinsic difficulties in sustaining lifestyle changes. This has provided PBCC the opportunity to review whether they have the resources to address some of the follow-up support needs of clients after they attend the Living Well course. Participants who returned to PBCC within the 12 month follow-up period, benefitted by reporting a greater improvement in HRQoL and MYCaW scores, and an improved understanding of how to make healthy lifestyle changes to suit their individual circumstances.

In regards to the NCSI priorities, it is intended that the data reported in this service evaluation will contribute to informing all of them ('Information and support from the point of diagnosis; Managing the consequences of treatment; Promoting recovery; Sustaining recovery; Supporting people with active and advanced disease; Improving survivorship intelligence'). Finally this report demonstrates how a patient centred model of support can be evaluated to provide relevant information to commissioners.

Participant satisfaction:

- Participants were very satisfied with the course content, course delivery and resources provided, which often exceeded their needs and expectations.

Participant outcomes:

- The PB-WPA model successfully encompassed and supported all the types of concerns participants arrived with.

-
- The most frequently reported participant concerns were psychological and emotional, about their wellbeing and about their physical health.
 - On average, participants experienced statistically and clinically significant improvements in their MYCaW concern and wellbeing scores, and total HRQoL scores, which remained improved over the 12 month follow-up.
 - The aspects of HRQoL that were most likely to improve after attending the Living Well course were spiritual, emotional and functional wellbeing.
 - Supporters had their own profile of concerns, namely psychological and emotional, supporter specific concerns and practical concerns. Concerns were as severely rated as those from participants with a diagnosis of cancer and also showed statistically significant average improvements throughout the 12 month follow-up.
 - The small group of participants with metastatic disease reported significant improvements in their MYCaW concern scores, in line with the whole evaluation group and a significantly greater improvement in HRQoL over 12 months compared to participants with primary cancer.
 - Participants who returned for more support from PBCC were in more need of support than those who did not return. They were more likely to have poorer HRQoL at baseline and rate their concerns more severely.
 - Participants who returned to PBCC experienced more improvement in HRQoL that was likely to be clinically significant. These participants also had a greater degree of improvement in their MYCaW concerns, compared to non-returners.
 - Over half of the participants experienced new concerns over the 12 month follow-up period. Concerns were most frequently associated with psychological and emotional and physical issues. Furthermore, at 12 months, participants were still experiencing a range of health issues.

Participant experience:

- Key features of the course which were most helpful were 'sharing with others'; 'the course in general'; 'nutrition and food'; 'the doctors' talk'; 'relaxation, meditation and self-help'.
- The majority of participants reported improvements in close relationships as a result of attending the Living Well course, which included being more open, talking more freely and placing a greater value on close relationships.
- For some participants the Living Well course helped clarify what was important to themselves, which occasionally caused further conflict within a close relationship.
- The Living Well course facilitated mutual benefits for the patient-supporter dyad, including better communication and an understanding of each other's needs, which led to more effective support. The supporters were also more likely to have an increased awareness of the importance of their own wellbeing and how to make healthy lifestyle changes.

-
- Many participants reported feeling more confident and able to seek help from medical professionals when they needed it.
 - Some participants were empowered to take responsibility for their own wellbeing and to be more aware of the boundaries of what the NHS can and cannot offer. Approximately 50% of the original group were motivated to access their own supportive, health and community based groups and resources.
 - Participants wanted a range of flexible and accessible support after attending the Living Well course, which included practical suggestions, DVD based resources, more communication from PBCC, more communication with other clients on their Living Well course and more PBCC centres closer to where they lived.

Lifestyle changes:

- Many participants found the education and experience of trying out self-help techniques on the Living Well course beneficial and reported that this enabled them to regain control over aspects of their life. There was a sustained increase in the number of self-help techniques being practised through to 12 months after the course.
- Education from the Living Well course motivated the majority of participants who weren't exercising to start exercising and for active participants to exercise more effectively. Many participants were inspired to combine physical activities with increased engagement in group-based social activities.
- The nutrition education on the Living Well course had an immediate positive impact on participants, who made noticeable dietary improvements over a period of 6 weeks – 3 months.
- Participants were often more aware of what a healthy diet consists of, although challenges to maintaining a healthier diet were most frequently reported 3-6 months after the Living Well course.

Barriers to change:

- Returning to work or a deterioration in health, often side-effects of chemotherapy, commonly led to less exercise being undertaken.
- More support from family and friends, and PBCC is needed for participants to sustain initial improvements in their eating habits.
- Other challenges to maintaining the use of self-help techniques included time pressures from work and family commitments, and forgetting the techniques, often due to side-effects of chemotherapy.

10 Recommendations

The recommendations below are split into 3 domains, in order of priority. Firstly to maximise the short and long-term impact of the Living Well course, areas of service provision for review are highlighted. Future evaluation recommendations are made in light of the commissioning landscape, and evidence gaps exist that were not fully answered in this evaluation. Research recommendations take into account the more in-depth exploration that could be carried out, from which data would continue to inform service development within PBCC.

Service Development:

1. To review the finance section of the course with the aim of it being rated as highly as the other aspects of the course. As PBCC services extend throughout the UK, the sociodemographic profile of participants is likely to extend to a lower socioeconomic group, where support about finances may play a more important role within the PB-WPA.

2. Review the proportion of supporters attending the Living Well courses and whether this can be increased. The benefit to supporters' own health and wellbeing, to them becoming more effective at supporting their loved one, and the knock-on effect for the person with cancer attending with a supporter has been clearly demonstrated within the service evaluation.

3. To review the types of barriers to initiating and sustaining healthy lifestyle changes reported to identify if any barriers could be addressed by PBCC providing more follow-up support. Furthermore, to identify which of the resources participants have suggested in the evaluation could be provided by PBCC. Providing support to participants after they had finished their Living Well course, increased the level of improvement in their HRQoL, and helped them to sustain their healthy lifestyle changes.

4. To review the 'crux' moments reported by participants that most challenged them in making and sustaining healthy lifestyle changes, and consider these as initial stages at which to provide a range of additional support, to maximise the effective use of financial resources.

Future Evaluation:

5. To find a more appropriate tool to measure HRQoL of supporters.

6. To economically evaluate the impact of the Living Well course. Economic impact data will provide more information that is increasingly needed to determine the benefit of commissioning services.

7. To carry out further evaluation on a greater number of clients with metastatic disease, to determine more accurately how the Living Well course benefits this group of clients.

Future Research:

8. To carry out an in-depth exploration of the benefit of the Living Well course, in particular:

- what strategies clients are using to overcome barriers to sustaining healthy lifestyle changes
- to explore positive wellbeing and measure positive traumatic growth

9. To explore the benefit of the other courses offered at PBCC.

Measure Yourself Concerns and Wellbeing (MYCAW)

First Form

Full name

Date

* * * * *

Now that you have thought about the six key areas, please write down one or two specific concerns which trouble you most or are move important to you.



1.

2.



Please circle a number to show how severe each concern or problem is now:

This should be YOUR opinion, no one else's!

Concern or problem 1:



	0	1	2	3	4	5	6	
Not bothering me at all								Bothers me greatly

Concern or problem 2:

	0	1	2	3	4	5	6	
Not bothering me at all								Bothers me greatly

Wellbeing:

How would you rate your general feeling or wellbeing now? (How do you feel in yourself?)

	0	1	2	3	4	5	6	
As good as it could be								As bad as it could be

Measure Yourself Concerns and Wellbeing (MYCAW)



Follow up Form

First name Today's date



Look overleaf at the concerns that you wrote down before (please do not change these).

On this form, please circle a number to show how severe each of those concerns or problems are now:

Concern or problem 1:



	0	1	2	3	4	5	6	
Not bothering me at all								Bothers me greatly

Concern or problem 2:

	0	1	2	3	4	5	6	
Not bothering me at all								Bothers me greatly

Wellbeing:

How would you rate your general feeling or wellbeing now? (How do you feel in yourself?)

	0	1	2	3	4	5	6	
As good as it could be								As bad as it could be

Other things affecting your health

The treatment that you have received here may not be the only thing affecting your concern or problem. If there is anything else which you think is important, such as changes which you have made yourself, or other things happening in your life, please write it here.

What has been most important for you?

Reflecting on your time with this Centre, what were the most important aspects for you?

Thank you for completing this form.

13 Appendix 3 - FACIT-SpEx

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

<u>PHYSICAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
<input type="checkbox"/>	I have a lack of energy.....	0	1	2	3	4
<input type="checkbox"/>	I have nausea.....	0	1	2	3	4
<input type="checkbox"/>	Because of my physical condition, I have trouble meeting the needs of my family.....	0	1	2	3	4
<input type="checkbox"/>	I have pain.....	0	1	2	3	4
<input type="checkbox"/>	I am bothered by side effects of treatment.....	0	1	2	3	4
<input type="checkbox"/>	I feel ill.....	0	1	2	3	4
<input type="checkbox"/>	I am forced to spend time in bed.....	0	1	2	3	4
<u>SOCIAL/FAMILY WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
<input type="checkbox"/>	I feel close to my friends	0	1	2	3	4
<input type="checkbox"/>	I get emotional support from my family.....	0	1	2	3	4
<input type="checkbox"/>	I get support from my friends	0	1	2	3	4
<input type="checkbox"/>	My family has accepted my illness	0	1	2	3	4
<input type="checkbox"/>	I am satisfied with family communication about my illness.....	0	1	2	3	4
<input type="checkbox"/>	I feel close to my partner (or the person who is my main support).....	0	1	2	3	4
<input type="checkbox"/>	<i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box <input type="checkbox"/> and go to the next section.</i>					
<input type="checkbox"/>	I am satisfied with my sex life.....	0	1	2	3	4

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

<u>EMOTIONAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
Q1	I feel sad.....	0	1	2	3	4
Q2	I am satisfied with how I am coping with my illness.....	0	1	2	3	4
Q3	I am losing hope in the fight against my illness.....	0	1	2	3	4
Q4	I feel nervous.....	0	1	2	3	4
Q5	I worry about dying.....	0	1	2	3	4
Q6	I worry that my condition will get worse.....	0	1	2	3	4

<u>FUNCTIONAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
Q7	I am able to work (include work at home).....	0	1	2	3	4
Q8	My work (include work at home) is fulfilling.....	0	1	2	3	4
Q9	I am able to enjoy life.....	0	1	2	3	4
Q10	I have accepted my illness.....	0	1	2	3	4
Q11	I am sleeping well.....	0	1	2	3	4
Q12	I am enjoying the things I usually do for fun.....	0	1	2	3	4
Q13	I am content with the quality of my life right now.....	0	1	2	3	4

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

		Not at all	A little bit	Some- what	Quite a bit	Very much
201	I feel peaceful.....	0	1	2	3	4
202	I have a reason for living.....	0	1	2	3	4
203	My life has been productive.....	0	1	2	3	4
204	I have trouble feeling peace of mind.....	0	1	2	3	4
205	I feel a sense of purpose in my life.....	0	1	2	3	4
206	I am able to reach down deep into myself for comfort.....	0	1	2	3	4
207	I feel a sense of harmony within myself.....	0	1	2	3	4
208	My life lacks meaning and purpose.....	0	1	2	3	4
209	I find comfort in my faith or spiritual beliefs.....	0	1	2	3	4
210	I find strength in my faith or spiritual beliefs.....	0	1	2	3	4
211	My illness has strengthened my faith or spiritual beliefs....	0	1	2	3	4
212	I know that whatever happens with my illness, things will be okay.....	0	1	2	3	4
213	I feel connected to a higher power (or God).....	0	1	2	3	4
214	I feel connected to other people.....	0	1	2	3	4
215	I feel loved.....	0	1	2	3	4
216	I feel love for others.....	0	1	2	3	4
217	I am able to forgive others for any harm they have ever caused me.....	0	1	2	3	4
218	I feel forgiven for any harm I may have ever caused.....	0	1	2	3	4
219	Throughout the course of my day, I feel a sense of thankfulness for my life.....	0	1	2	3	4
220	Throughout the course of my day, I feel a sense of thankfulness for what others bring to my life.....	0	1	2	3	4
221	I feel hopeful.....	0	1	2	3	4
222	I feel a sense of appreciation for the beauty of nature.....	0	1	2	3	4
223	I feel compassion for others in the difficulties they are facing.....	0	1	2	3	4

14 Appendix 4 - In house evaluation form

**LIVING WELL WITH AND BEYOND CANCER
RESIDENTIAL COURSE
EVALUATION FORM**

Person with cancer / Supporter / Helper Supporter (please circle) **Course Date:**

We would be grateful if you could take some time to complete our evaluation form. We aim to provide the best possible advice and care and your feedback is invaluable in helping us to continually improve our service.

Please complete ALL sides of this form.

Please return to Reception

Thank you

**Using the assessment scale provided, please grade our 'services' by circling the appropriate number. (*Where 1 = poor and 5 = excellent*)
You do not have to add comments but if you want to, please do.**

Your welcome at the Centre	1	2	3	4	5
Comments					
The accommodation	1	2	3	4	5
Comments					
The food	1	2	3	4	5
Comments					
The Centre staff	1	2	3	4	5
Comments					
Course organisation	1	2	3	4	5
Comments					
Administration	1	2	3	4	5
Comments					
Course Presentation	1	2	3	4	5
Comments					
Standard of handouts & flip charts	1	2	3	4	5
Comments					
Any other general comments/suggestions for improvements?					

Group Sessions

**Please let us know how helpful you found any of the sessions by circling the relevant number
(Where 1 = poor and 5 = excellent)**

Please add comments if you wish

Relaxation	1	2	3	4	5
Comments					
Healthy Eating	1	2	3	4	5
Comments					
Mindfulness	1	2	3	4	5
Comments					
Benefits of Exercise	1	2	3	4	5
Comments					
Mindful Movement	1	2	3	4	5
Comments					
Emotional/Psychological Health	1	2	3	4	5
Comments					
Imagery	1	2	3	4	5
Comments					
Financial Welfare	1	2	3	4	5
Comments					
Nature walk	1	2	3	4	5
Comments					
Impact of cancer on relationships	1	2	3	4	5
Comments					

Please let us know your impressions of the course
(Where 1 = poor and 5 = excellent)
Please add comments if you wish

How well did the course meet your needs?	1	2	3	4	5
Comments					
How well did the course meet your expectations?	1	2	3	4	5
Comments					
Was there anything you found particularly helpful or unhelpful about the course?					
Please comment					
How did you find the pace of the course? (Please circle)	Just right	Too fast	Too slow	Don't know	
Were there any other talks or activities you would have liked to have done on the course that weren't on the programme? If so please describe below:					

Finally please let us know your impression of the staff and facilitators
(Where 1 = poor and 5 = excellent)
Please add comments if you wish

Course staff

Nurse Therapist	1	2	3	4	5
Name of Nurse Therapist					
Comments					
Course Facilitator 1	1	2	3	4	5
Name of Facilitator					
Comments					
Course Facilitator 2	1	2	3	4	5
Name of Facilitator					
Comments					
Any further comments on the course programme or content, things you particularly liked or disliked? (Please continue on a separate sheet if necessary.)					

15 Appendix 5 - 6 week participant experience questionnaire

Participant experience survey

Please fill in the questions below, which will help us to understand which parts of the course were most valuable for you and which areas we could improve. If for any reason you do not want to answer a question, then please leave it blank.

1. Has your experience of this course helped you to change your diet since joining this course?

(please circle)

YES NO

Any comments:

.....
.....
.....

2. Has your experience of this course helped you to take more exercise since joining the course?

(please circle)

YES NO

Any comments:

.....
.....
.....

3. Has your experience of your course had any effect on your close relationships? *(please circle)*

YES NO

Any comments:

.....
.....
.....

4. Has your experience of your course helped you to practise any of the other techniques learned in this group? *(please circle)*

YES NO

Any comments:

.....
.....
.....

5. Has anything else changed since doing the course that you want to tell us about? *(please circle)*

YES NO

If YES, please explain:

.....
.....
.....

6. How helpful was the handbook *during* the course? *(please circle)*

- Very helpful
- Helpful
- Not very helpful
- Don't know

7. How helpful was the handbook *after* the course? (please circle)

- Very helpful
- Helpful
- Not very helpful
- Don't know

8. Have you used the action plans you created on the course? (please circle)

YES NO

9. How helpful was the follow-up support phone call you received a few weeks after you finished the Living Well course? (please circle)

- Very helpful
- Helpful
- Not very helpful
- Don't know

Any comments:

.....
.....
.....

10. Is there anything else that you would like to comment on regarding your experience of the Living Well With and Beyond Cancer Course?

.....
.....
.....

Thank you very much for filling in this form.

16 Appendix 6 - Lifestyle questionnaire

Lifestyle Questions:

1. Please describe your current diet by filling in the following boxes:

Please write NUMBER of times a week (e.g. write "4" if you have something 4 times a week.)

Food type	Number of times per week
Alcohol (e.g. glass of wine or beer)	
Barbequed or griddled foods	
Caffeine (e.g. number of cups of coffee/tea or caffeinated soft drink)	
Dairy produce (e.g. cheese, butter)	
Damaged fats (e.g. in processed fatty foods)	
Healthy fats (e.g. olive oil, nuts and seeds)	
Herbs and spices (e.g. garlic, ginger, chilli)	
Processed meats (e.g. salami, processed burgers)	
Protein foods (e.g. white meat, fish, nuts)	
Pulses (e.g. lentils)	
Red meat (e.g. steak)	
Refined grains and sugars (e.g. in processed bread, cakes)	
Salt (added to food)	
Soya products (e.g. tofu, miso, tempeh)	
Vegetables and fruit	
Water (e.g. a cup of water)	
Whole grains (e.g. wheat, rice)	

2. How many times per week do you take part in physical activity for 30 minutes or more? (please tick boxes below)

Times of exercise a week	Tick
0	
1-2	
3-4	
4-5	
5+	

What type of exercise do you do?

.....

3. Are you using any self-help or stress management techniques?

YES NO (*please circle*)

If yes, please give the number of times a week for each thing you do:

Type of self-help/Stress management technique	Number of times a week
Relaxation	
Meditation	
Visualization/Imagery	
Other, e.g. listening to music, reading, gardening	

17 Appendix 7 - 12 month participant experience questionnaire
Living Well with the Impact of Cancer course, 12 months additional questionnaire

Now we have reached 12 months since you attended your Living Well course, we are at the end of this evaluation project. To further understand the views and needs of people attending the centre, we have a few questions that we would like to ask you.

Some questions are specific to people with cancer, some are specific to supporters. These are clearly stated but please answer any questions that you feel apply to you, or just write N/A in the box if the question is not relevant.

Q1. This question is aimed at **ALL** clients of Penny Brohn Cancer Care.

Reflecting back over the last 12 months is there any particular activity that you have done as a result of attending the Living Well Course (e.g. joined a choir, joined a meditation group...).

Q2. This question applies to **ALL** clients of Penny Brohn Cancer Care.

Over the past year, aside from your visit to Penny Brohn Cancer Care have you been on any **other** courses/attended any **other** centres offering support for people with cancer and their supporters?

- Yes
- No

If yes please state what you have done:

Q3. This question applies to **ALL** clients of Penny Brohn Cancer Care.

Sometimes it can be challenging to continue with the healthy lifestyle changes recommended on the Living Well Course. If this was the case for you, please outline your experience below.

Q4. This question is aimed at **ALL** clients of Penny Brohn Cancer Care.

Reflecting on the past year, would any of the following sources of information have been helpful to you after leaving the Living Well Course? (tick as many options that apply.)

- Copies of recipes to take away with you
- Online video demonstrations of cooking foods- e.g. you tube videos
- Copies of the PowerPoint slides from the talks on the course
- A DVD to take home containing key pieces of information from the course, which you can play anytime. Please state which pieces of information you'd like in the comments box below.
- A smartphone "app" for breathing/ meditation/ relaxation exercises for you to have whenever you need it
- Regular (e.g. weekly or biweekly) short communications such as peptalks and pointers on how to sustain healthy lifestyle changes
- Penny Brohn Cancer Care online support forums for you to join
- A leaflet for you to give to your other healthcare providers (oncologists, GPs, nurses) containing scientific evidence and appropriate information about Penny Brohn Cancer Care.
- N/A

Any other comments?

Q5. This question is aimed at **ALL** clients of Penny Brohn Cancer Care.

Looking back over the last 12 months at the SMART goals you set yourself while you were on the Living Well course, have you achieved these goals? (Look back at the Living Well Handbook that you were given to check what these were if you cannot remember).

- Completely
- Partially
- Not at all
- Can't remember

Please give details/ any comments:

Q6. This question is aimed at the **PERSON LIVING WITH CANCER.**

Do you feel your experience of the Living Well course has made a difference to you in terms of how you have accessed medical services e.g. GPs/hospital over the last 12 months?

- Yes
- No
- Don't know

If yes please state how:

Q7. This question is specifically aimed at the **PERSON LIVING WITH CANCER.**

What best describes your current state of health? (you can tick more than one.)

- Undergoing hospital treatment for primary tumour (e.g. chemotherapy, radiotherapy, surgery and reconstructive surgery.)
- Hormone treatment only but have finished all other cancer treatments.
- Have finished all hospital cancer treatment in the past year and have no sign of cancer
- Have finished hospital cancer treatment over a year ago and have no sign of cancer.
- Local recurrence has been detected
- Distant metastasis has been detected
- Undergoing hospital treatment for metastatic disease
- I am having palliative treatment
- I have finished cancer treatment but am still experiencing side effects of treatment.

Did we miss your situation out? Please outline it for us below.

Q8. Please answer this question if you are a **SUPPORTER**, otherwise put N/A in the box below.

Are there any particular aspects of the Living Well course that have helped you cope with supporting a person with cancer? (Please write in the box below.)

Q9. Please answer this question if you are a **SUPPORTER**. Otherwise put N/A in the box below.

In this past year since attending the Living Well course, are there any particular ways you have thought of which Penny Brohn Cancer Care could have supported you further, or that you would have found helpful? (Imagine you are in an ideal world.)

Q10. Please answer this question if you are a **SUPPORTER**, or put N/A in the box below.

Is there anything you would say to a supporter who is thinking of coming on the Living Well course but isn't sure that it is for them?

This is the end of the questionnaire.

Are there any other comments you would like to make?

Future Information

Would you like to receive a summary report of the results from this evaluation (anticipated Spring 2013). As all questionnaires are anonymous, no individuals will be identifiable in this.

Yes

No

We are interested in continuing to follow people that have attended Penny Brohn Cancer Care for longer than this one year time point, due to the high value of the information and comments received in this evaluation. Understanding the longer term needs of people with cancer, survivors and their supporters is currently poorly understood.

Please tick below if we can contact you again in a year's time. Please note that all personal information from this evaluation is kept in strict accordance with the Data Protection Act. Your support from Penny Brohn Cancer will not be affected in anyway by not ticking the box.

I consent for you to contact me in one years time if this evaluation is continued.

Thank you for your time!

The information that you have given us is **extremely valuable** and we very much appreciate you taking the time to respond to this questionnaire.

If you have any further questions or comments please contact Dr Helen Seers, Penny Brohn Cancer Care, 01275 370123 or email Helen.seers@pennybrohn.org

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