Penny Brohn UK

Service evaluation of the Wellness Package:
A 12 month Longitudinal Retrospective

May 2016
Authors

Rachel Jolliffe is the Senior Research & Evaluation Officer at Penny Brohn UK. Rachel has worked in the Research & Evaluation Department since 2012, working on the development of Penny Brohn UK’s programme of service evaluation and reporting to the charity’s major funders. Rachel has a First Class BSc in Psychology from the University of the West of England and an MSc in Social and Organisational Psychology from the University of Exeter.

Helen Seers is the Research & Evaluation Lead at Penny Brohn UK. Helen’s current role includes leading the ongoing research and evaluation programme of work at Penny Brohn UK and the development of academic publications to support this. Helen graduated from Bristol University in 1998 with a First Class BSc in Experimental Psychology and then gained a PhD from the same university in 2002. After this time, Helen continued to work at Bristol University as a research psychologist in several posts in health psychology. In 2004 she joined Bristol Cancer Help Centre, now known as Penny Brohn UK.

Jo Durrant is the Information & Evaluation Officer at Penny Brohn UK. Jo has worked in the Research & Evaluation Department since 2012, working on the development of Penny Brohn UK’s service evaluation programme and the production of evidence-based information on self-management support options for people with cancer. Jo has a First Class BSc in Psychology from the University of Southampton.

Hannah Sweetnam is the Brand & Web Marketing Officer at Penny Brohn UK. Hannah has a BA Hons in Multimedia Journalism from Bournemouth University and a background in creative marketing and communications.

Michael Connors is the Director of Service Innovation and Academy at Penny Brohn UK. His core training is in Holistic and Integrative methods in counselling and psychotherapy and this has led to his ongoing interest in a whole person approach to health and wellbeing. After many years in education, as Lecturer in Psychological Therapies and Counselling, he started at Penny Brohn UK as a community course facilitator working with people affected by cancer in hard to reach communities in Bristol. From there he became Head of Education and then Director of Services, where he redesigned services in alignment to the National Cancer Survivorship Initiative and led the expansion of the Penny Brohn UK Living Well Services across the UK.

Corresponding author: Helen.Seers@pennybrohn.org.uk
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Foreword
Executive Summary
Introduction
Foreword

Michael Connors
Director of Service Innovation and Academy
Penny Brohn UK, May 2016

In 2014, the NHS England Five Year Forward View set out a clear ambition for stronger partnerships with the voluntary sector, to support people and communities in managing their own health and wellbeing. We welcome this wholeheartedly, as for many years Penny Brohn UK has supported people with cancer to manage the consequences of the disease and its treatment. We have explored how self-management of health and wellbeing can help alleviate some of the challenges that come with cancer, and respond to the increasing numbers of people living with and beyond cancer in the UK. As an active participant in the National Cancer Survivorship Initiative, Penny Brohn UK set out to explore and test how we could find effective and affordable interventions that would act as an integrated part of cancer services. These became our Living Well Services.

This report explores how the Penny Brohn UK Living Well services were redesigned and developed in response to previous evaluation work. It outlines how adopting a Whole Person Approach to self-management after a cancer diagnosis can be achieved with ongoing support. It sets out to demonstrate some of the untapped resources at the heart of a holistic, person-centred approach to health and wellbeing.

The starting point for the redesign of our Living Well Services was a previous evaluation of our Living Well course, published in 2013 with the University of Westminster. This evaluation found our self-management enabling ‘Living Well’ course to be an effectively designed intervention, which demonstrated clinically significant outcomes in health and wellbeing. This earlier evaluation also highlighted the need for ongoing support to maintain self-management of health and wellbeing. Therefore, we sought funding to explore this under the title of the ‘Wellness Package’. We received funding from the Department of Health and over an 18 month period, further tested our Living Well Services, incorporating enhanced Follow-Up services after our Living Well course.

This report sets out the findings from our evaluation of the Wellness Package in detail and points to further developments and possible outcomes. We are glad to see that the effectiveness of our services continues to shine through and that we are beginning to gather some economic data, which tentatively begins to point to the inherent economic value of adopting a holistic approach to health.

I am delighted that, six years on from our first test of community Living Well courses, we have come so far. However, I am acutely aware of the challenges we face in the years ahead, to deliver the support that people affected by cancer need and deserve. We are delighted to be working with the Realising the Value programme to help shape new pathways of care that will begin to meet these challenges. I know that Penny Brohn UK will continue, in its 36th year, to help meet the needs of as many people affected by cancer as we can, helping them to live as well as they can. That is what really matters to us.
Executive Summary

Dr. Helen Seers
Research and Evaluation Lead
Penny Brohn UK, May 2016

Penny Brohn UK’s Wellness Package was designed to help all people (over 18 years of age) with cancer and their supporters to live well with the impact of cancer, by providing access to the person-centred Bristol Whole Life Approach: holistic support for mind, body, spirit and emotions. Crucially, the Wellness Package is a combination of Penny Brohn UK’s Living Well course and additional subsequent access to Follow-Up support. This combination enables long-term holistic support, with initial engagement and then re-connection with the Bristol Whole Life approach. The Wellness Package therefore ensures that Penny Brohn UK clients experience a connected and long-term supportive service, enabling reassurance and reconnection where needed in an individual’s journey with cancer.

The Penny Brohn UK Wellness Package ran for 18 months, between July 2014 and January 2016, and was supported by funding from the Department of Health’s Innovation, Excellence and Strategic Development (IESD) fund. The Wellness Package delivered 60 Living Well courses across the UK (reaching 519 people), and provided 12 months’ of Follow-Up support. The intended outcomes of the Wellness Package were A) to enable clients to gain the knowledge, skills and confidence to self-manage their long-term health condition(s); B) to support and maintain an improvement in health related quality of life, cancer related concerns and positive lifestyle changes (diet, exercise, self-help techniques and supporting relationships); and C) to potentially reduce wider healthcare service use by the Wellness Package enabling points A and B.

A service evaluation of the Penny Brohn UK Wellness Package was conducted to measure intended outcomes, and this evaluation forms the basis of this report. This evaluation used a mixed methods approach with a range of validated questionnaires in a pre-post data collection method design. It observes the impact of the Living Well course, the Follow-Up support and also captures 12 month retrospective views, allowing clients to reflect back on their whole experience of the Wellness Package. No control group was used, so this evaluation represents an observation of the people who responded to the evaluation. The overall impact of the Wellness Package can be summarised as follows:
Executive Summary

A) Self-management was supported and enabled. A significant change in Patient Activation Measure (PAM) scores was found, with clients at the lowest levels of ‘activation’ before the course showing the greater levels of improvement. Also, at 6 weeks and 12 months after the Living Well course, 86% and 90% respectively said that their course experience had enabled them to self-manage their health more effectively. Wider issues around self-management were also explored qualitatively; the main facilitators to self-management were recorded as: information about diet, exercise and self-help techniques, and gathering the knowledge, skills and confidence to make changes. The Follow-Up support had a positive benefit on motivating clients to carry on with the positive changes they had made.

B) Health related quality of life was significantly improved when MYCaW (Measure Yourself Concerns and Wellbeing) questionnaire scores were measured at 6 weeks and 12 months post Living Well course. Cancer related concerns were also significantly reduced over the same time points; the most commonly reported concerns were psychological and emotional. Positive lifestyle changes (in terms of people’s perception of their diet, exercise, use of self-help techniques and relationships) were reported at 6 weeks and maintained at 12 months post Living Well course. These changes were further maintained by experience of Follow-Up support provided as part of the Wellness Package.

C) Emerging evidence shows a potential reduction in healthcare service use after attending services on the Wellness Package. A reduction in self-reported healthcare service use was seen when healthcare service use before the Wellness Package was compared to 12 months post Living Well course. However, these results should be treated with caution as many clients’ health improved during the course of the 12 months, with the majority having finished active treatment by this time point. More robust data collection using actual healthcare service use rather than self-reported retrospective use should be gathered in future evaluation and research.

Overall, the Wellness Package ran successfully over 18 months and was highly rated in terms of meeting the needs and expectations of people with cancer and their supporters. The evidence gained from this evaluation will be used to feed into a broader context; a current culture change in healthcare heralded by the NHS Five Year Forward view and projects such as Realising the Value, which highlight the importance of person centred, self-management enabling services like that of the Wellness Package.
Introduction

Cancer care in the UK

Approximately 2 million people in the UK are living with cancer, with numbers predicted to increase by approximately one million per decade from 2010 to 2040, leading to around four million people living with cancer by 2030 [1]. Those living with and beyond cancer often have poorer wellbeing and health when compared to the general population, and often feel in need of further support at the end of medical treatment [1, 2]. Unmet needs of people with cancer have been highlighted as psychological, emotional, physical, sexual, occupational [3, 4], social [5] and existential [6, 7]. With an increasing population of people with cancer with unmet needs [8], evidence that patients want to be more informed and involved with their own care [9, 10], and a challenging healthcare funding environment [11,12], there is a clear need for cancer survivorship services to enable people to self-manage their condition, enabling better health and care outcomes.

Penny Brohn UK

Penny Brohn UK is the leading UK charity specialising in helping people to live well with cancer, particularly focusing on self-management education, supporting and enabling people to find their own route though the experience of cancer. Penny Brohn UK was founded in 1980 by Penny Brohn and Pat Pilkington; two pioneering women whose work has changed the way people view support for people with cancer. Penny Brohn, herself a cancer survivor, believed that care was needed for “… the mind, the spirit, the emotions, the heart and the soul” as well as the body. This was the start of the Bristol Whole Life Approach.

The Bristol Whole Life Approach addresses each part of a person; mind, body, spirit and emotions, recognising that these parts are interconnected and work together to support the immune system. If people keep themselves well in each of these areas, they are able to take back some control over their health and wellbeing, build their resilience and live well with the impact of cancer.

There is substantial research evidence behind the Bristol Whole Life Approach in terms of its lifestyle advice (diet, exercise and self-help techniques). There is a vast amount of research which shows the benefits of physical activity for people with cancer, with improvements reported in areas such as anxiety [13], fatigue [14], quality of life [15, 16] and immune function [17]. Other studies have found that physical activity can reduce risk of cancer recurrence and mortality [18, 19]. There is also an increasing amount of research showing the importance of a healthy balanced diet, which can greatly reduce the risk of cancer and cancer recurrence [20, 21]. Lastly, self-help techniques such as meditation and mindfulness have been shown to benefit people with cancer, with reported improvements in areas such as depression, anxiety and stress [22-24].
Introduction

Development of the Penny Brohn UK Wellness Package

The Penny Brohn UK Wellness Package was developed to support people with cancer and their close supporters to live well with the impact of cancer and its treatments. The Wellness Package comprises Penny Brohn UK’s flagship ‘Living Well with the Impact of Cancer’ course (‘Living Well course’) plus 12 months of ‘Follow-Up’ support.

The Living Well course was launched in 2010 in response to the National Cancer Survivorship Initiative (NCSI) Vision report [6]. The NCSI vision was that by 2012, people living with and beyond cancer would be “…supported to live as healthy and active a life as possible for as long as possible”. This would involve a shift towards supported self-management and an emphasis on measuring experiences and outcomes through the use of Patient Reported Outcome Measures (PROMS) rather than clinical measures.

The Living Well course was designed to be flexible so it can run in different formats at different locations in the UK. Currently the course is run over two consecutive days, or over two or three weeks. Living Well courses are run by fully trained facilitators (AptEd accredited) and aim to provide clients with a toolkit of techniques that can help address the eight components of Penny Brohn UK’s Whole Person Model (see Figure 1 below).

Figure 1. Penny Brohn UK Whole Person Model
Introduction

Course participants are shown simple steps they can take to address each of these components:

- Body; healthy eating and physical activity
- Spirit; faith, connecting with joy and purpose
- Mind and emotions; feeling in control, managing stress
- Relationships and community; social connections, identifying sources of support
- Practical issues and environment; financial stability, good work/life balance

In addition, course participants are taught simple but effective self-help techniques:

- Relaxation
- Meditation
- Mindfulness
- Imagery

The course content is compiled in a comprehensive Living Well course Handbook, which was upgraded in Spring 2015 to comprise an A5 ring binder with a workbook (including self-care planning), space for note taking and ‘next steps’; in addition to the course content. From this, clients are able to fully utilize the Handbook after the course to support positive lifestyle changes. If clients are interested in the research behind the Bristol Whole Life Approach, they are directed to the Penny Brohn UK website where they can download a comprehensive reference list which directly links to the content of the Handbook.

In 2013, Penny Brohn UK published the results of a longitudinal service evaluation of the Living Well course, in collaboration with the University of Westminster [25, 26]. Participants were clients attending Living Well courses running between August 2011 and January 2012. One hundred and seventy one participants were recruited, including men and women, people with cancer and supporters, aged from 18 to over 80 years, and representing more than 20 different cancer types including breast, lung, prostate and bowel.

The evaluation showed that the Living Well course:

- Improved Health Related Quality of Life (HRQoL)
- Reduced the severity of cancer related concerns
- Improved wellbeing
- Led to improvements in diet, exercise and use of self-help techniques
- Improved relationships and communication with family, friends and medical professionals

The evaluation results also showed that clients started experiencing difficulties with maintaining lifestyle changes at around 3-6 months after the Living Well course. Further to this, clients who returned to Penny Brohn UK for more support after the Living Well course had bigger improvements in their HRQoL and wellbeing at the 12 month follow-up [26].
Introduction

Penny Brohn UK Wellness Package

The Penny Brohn UK Wellness Package was designed in direct response to the results of the robust Living Well service evaluation, showing a need to support people long-term, and particularly around 3 to 6 months post Living Well course. The aim of the Wellness Package was to provide a longer term package of support to help clients maintain healthy lifestyle changes made after the Living Well course, leading to greater improvements in overall quality of life and wellbeing.

The Wellness Package included ongoing information and Follow-Up support, incorporating:

- 1:1 telephone appointment with a Nutritional Therapist and access to regular new recipes, cooking demonstrations and tips on how to eat well (email)
- 1:1 telephone appointment with a Doctor
- Physical activity tips and information (email)
- Tips for self-help techniques and how to alleviate common symptoms such as sleep problems (email)
- Group support via Follow-Up Days and Online Community
- Access to a dedicated Helpline
- Additional online resources and talks

The Wellness Package was designed to meet individual needs and requirements. Clients with further support needs could be signposted to specialist follow on services; in-depth residential courses, specialist day courses and additional 1:1 appointments including complementary therapies.

In addition to responding to the results of the Living Well service evaluation, the Wellness Package also responded to the framework for survivorship set out by the NCSI in 2013 [27].

The framework is set out in five different steps:

1. Information and support from the point of diagnosis
2. Promoting recovery
3. Sustaining recovery
4. Managing the consequences of treatment
5. Supporting people with active and advance disease
Introduction

The Wellness Package prioritised 2) promoting recovery and 3) sustaining recovery, but sought to encompass all five steps.

The Wellness Package was launched in 2014 with funding from the Department of Health’s (DH) Innovation, Excellence and Strategic Development (IESD) fund. The scope was to deliver 60 Living Well courses nationally throughout the UK, plus 12 months’ of Follow-Up support across five regions in the UK (including deprived areas), potentially reaching 720 participants over 18 months.

Aims of the evaluation

• To evaluate the overall impact of the Wellness Package, particularly looking at the impact of receiving Follow-Up support, gathering evidence from:
  • Living Well course
  • Follow-Up support
  • 12 month longitudinal retrospective questionnaire
  • To assess how well the Wellness Package responded to the priorities set out by the NCSI (see above)

Objectives of the evaluation

• Measure the impact of the Wellness Package on self-management.
• Monitor if levels of wellbeing, cancer related concerns and lifestyle changes are supported and maintained over 12 months due to the combination of Living Well Course and Follow-Up support provided.
• Assess whether the Wellness Package has changed clients’ use of healthcare services (contrasting before and after healthcare service use).
Part 2

Methods
Results
Discussion
Conclusion
Methods

Evaluation of the Wellness Package was carried out by the Research and Evaluation Department at Penny Brohn UK. The evaluation used a mixed methods approach, combining qualitative and quantitative data obtained from evaluation questionnaires. Questionnaires in the form of PREMS (Patient Reported Experience Measures), PCOMS (Patient Centred Outcome Measures) and PROMS (Patient Reported Outcome Measures) were used. An observational evaluation approach was taken, with no control group. A pre-post data collection design was used, gathering data before, during, immediately after, and 6 weeks and 12 months after service delivery.

There were three main parts to this evaluation:

• Evaluation of the Living Well Course
• Evaluation of the Follow-Up support
• 12 month longitudinal retrospective questionnaire looking at clients’ experiences of the Wellness Package (Living Well Course plus Follow-Up support)

All clients attending a DH funded or part funded Living Well course between July 2014 and January 2016 were given the opportunity to take part in the evaluation following Penny Brohn UK’s standard evaluation procedures.

The first invitation letter was sent via post at the point of booking confirmation onto a Living Well course. An information sheet was enclosed which explained the objectives of the evaluation, along with the pre-course evaluation forms. All evaluation at Penny Brohn UK is optional; clients were informed that they could opt out without affecting the support they received from Penny Brohn UK. If clients did decide to take part, they could send back their pre-course evaluation forms in an enclosed pre-paid envelope. Alternatively they could bring them along when they attended the course and hand them in to their course facilitator. From April 2015, clients also had the option of completing their evaluation forms online.

Follow-up questionnaires were sent to all clients 6 weeks after their Living Well course, irrespective of whether they had completed their pre-course questionnaires.

Clients attending courses between September 2014 and January 2015 were sent an additional follow up questionnaire 12 months after their Living Well course to look at the longer term impact of the Wellness Package. This questionnaire was sent out between September 2015 and January 2016 to coincide with 12 months after their attendance. This cohort was chosen to fit in with the DH funding and reporting window.
Methods

Data collection

Pre-Course evaluation forms

Measure 1: ‘Your details’
This measure collected additional demographic information not included on the Living Well course Booking Form, including:

- Religion
- Main language
- Working status
- Relationship status
- Disabilities
- Recent use of NHS services

Measure 2: Patient Activation Measure* (PAM*) (since April 2015)
PAM is an internationally used and validated Patient Reported Outcome Measure (PROM) measuring level of ‘activation’; the knowledge, skills and confidence to manage one’s own health [28]. Research from America has shown that higher levels of activation are associated with better long term health outcomes and reduced healthcare costs [29]. PAM scores range from 0 to 100, with higher scores indicating higher activation. Scores can also be transposed into a ‘level’ of activation ranging from 1 (overwhelmed and lacking confidence) to 4 (maintaining a healthy lifestyle). The 10-item PAM was used.

Evaluation forms completed at the start of the Living Well course

Used therapeutically as part of the Living Well course, both tools below helped clients to identify the areas where they needed the most support. These measures were completed at the start of the course, before any course content had been delivered.

Measure 1: MYCaW (Measure Yourself Concern and Wellbeing)
MYCaW is a Patient Centred Outcome Measure (PCOM) designed specifically for the evaluation of cancer support services and validated against an internationally used measure of health related quality of life [10]. It was developed in the UK and is also used by integrative cancer centres and cancer support centres in the US, Canada and Israel [30-32]. The MYCaW questionnaire was designed to measure the impact of cancer support services on the severity of people’s cancer related concerns and wellbeing. Severity of concerns and wellbeing are rated on a scale of 1 to 6, with 1 being the best and 6 being the worst.

Measure 2: Health & Wellbeing Wheel (since March 2015)
A Penny Brohn UK bespoke tool which asked people to rate all aspects of their health and wellbeing; Mind, Community, Body, Practical Issues, Spirit, Environment, Emotions and Relationships. This tool was designed to reflect the Bristol Whole Life Approach. Each area is rated on a scale of 1 to 6, where 6 is the best.
Methods

Evaluation forms completed at the end of the Living Well course

**Measure 1: End of course Patient Reported Experience Measure (PREM)**
A short PREM handed out at the end of the course which asked clients to rate all aspects of the course, for example, the food, staff, venue, organisation, handouts and sessions. Ratings were on a scale of 1 to 5, with 5 being the best. There were also additional open-ended questions; what was most helpful, what else clients would have liked on the course, and what main messages were taken away.

**6 weeks post-course follow-up evaluation forms**

**Measure 1: Health & Wellbeing Wheel**
As previously described; to calculate changes in ratings of health and wellbeing after the Living Well course.

**Measure 2: MYCaW**
As previously described; to calculate changes in ratings of health and wellbeing after the Living Well course. Additional open-ended questions on the follow up form asked clients whether there was anything else going on in their life that was affecting their health, and what they felt was most important about the course.

**Measure 3: PAM®**
As previously described; to calculate changes in level of ‘activation’ after the Living Well course.

**Measure 4: 6 week PREM**
A bespoke PREM designed to collect in-depth information on clients’ experience of the Living Well course and changes that may have happened in their life as a result. Collected data on:

- Diet
- Exercise
- Relationships
- Use of self-help techniques
- Lifestyle changes
- Activities started as a result of the course e.g. choir, yoga, support group
- Unexpected benefits of the course
- Ability to self-manage
- Challenges faced when making lifestyle changes
- Other things Penny Brohn UK could have done to provide support since the course
- Progress with SMART goals made on the course
- Additional open ended questions specifically for supporters
Methods

12 month post-course follow-up evaluation forms

Measure 1: MYCaW
As previously described; to calculate changes in scores in the longer term.

Measure 2: 12 month PREM
Bespoke PREM designed to collect in-depth information on:

- Diet
- Exercise
- Relationships
- Use of self-help techniques
- Lifestyle changes
- Activities started/maintained as a result of the course
- Ability to self-manage
- Challenges faced when making lifestyle changes
- Other things Penny Brohn UK could have done to provide support since the course
- Progress with SMART goals made on the course
- Other Penny Brohn UK services used in the past 12 months e.g. Follow-Up Days, Follow-Up emails, 1:1 appointments, group sessions
- What difference Follow-Up support from Penny Brohn UK has made
- Changes to work situation i.e. able to return to work in past 12 months
- Use of NHS services over past 12 months
- Additional open ended questions specifically for supporters

Additional measures used in evaluation

An additional PREM was administered at the end of the Follow-Up Days and a small ‘pop up’ questionnaire gathered feedback on the emails sent. Other services included in the Wellness Package (e.g. 1:1 appointments) and other services attended outside of the scope of the Wellness Package (e.g. follow-on courses at the National Centre) were not evaluated but clients were asked to reflect on all support received on the 12 month PREM.
Methods

Analysis

Quantitative analysis

Data were entered anonymously into password protected Excel files. Excel files were then opened in SPSS V20 for data cleaning and analysis.

Basic descriptive statistics were carried out where appropriate. PAM, MYCaW and Health & Wellbeing Wheel ratings were calculated at baseline (start of the course) and at the follow up time points. Non-parametric tests (Wilcoxon Signed Ranks and Friedman) were carried out to determine the statistical significance of any changes over time. PAM score changes were coded as meaningful (≥4) or not meaningful (<4) and stratified by baseline levels of activation.

Qualitative analysis

Qualitative MYCaW data were coded using the published Qualitative Analysis Guidelines [10] and entered in SPSS as a binary score. Qualitative data from the end of course PREM, Follow-Up Day PREM, and the 6 week and 12 month follow-up questionnaires, were thematically analysed by RJ and JD.
Results

This section is split into three parts:

- Living Well course evaluation results
- Follow-Up support evaluation results (emails and Follow-Up Days)
- 12 month longitudinal retrospective evaluation results of the Wellness Package (experience of the Living Well course plus Follow-Up support)

Numbers of people attending the elements of the Wellness Package

The Living Well course was delivered to 519 clients between July 2014 and January 2016 and 120 clients went on to attend a Follow-Up Day (between April 2015 and January 2016).

Living Well Course Evaluation Data

Living Well Course Demographics

Basic demographic information from 519 clients was collected on the Living Well course booking form. Additional in-depth demographic information was collected from 303 clients on the optional ‘Your Details’ form administered at the point of booking confirmation.

Client characteristics are summarised in Table 1 below. For this report, all data is for people with cancer and supporters combined, unless stated otherwise.
### Results

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#### Characteristics (Booking Form)

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#### Characteristics (Your Details)

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Table 1. Client characteristics collected on booking form (n=519) and additional optional questionnaire ‘Your Details’ (n=303). For some items, only the top categories are reported.
Results

Living Well Course Demographics - additional health information (not including supporters)

The aim of collecting this additional health information was to better understand clients’ baseline level of health before their course attendance.

In addition to collecting demographic information, the Your Details questionnaire also asked for information on current health/treatment status and recent healthcare usage.

The majority (48%) were undergoing active cancer treatment, 34% had finished active treatment within the last year, while 10% had finished treatment over a year ago. An additional 3% were having palliative treatment and 4% reported that they had chosen not to have conventional treatment. Fifty three percent reported that they were currently living with cancer (still evidence of cancer in the body), 47% said they were living beyond cancer (no evidence of cancer in the body).

On average, clients reported visiting their GP 2.6 times in the previous 3 months, their cancer team 5.5 times, and other NHS services 2.9 times. Reasons given for visiting these healthcare providers were cancer treatment (34%), side-effects of treatment (23%), advice about self-management of their condition (15%), unrelated to cancer (13%) and other (15%).

End of Living Well course PREM

Data were collected from 430 clients and demonstrated high levels of satisfaction; no aspect of the course had a mean rating of less than 4.2/5. In addition to this, clients rated the course as 4.5/5 for meeting their needs and 4.5/5 for meeting their expectations. The majority (85%) rated the pace of the course as ‘just right’.

Additional open-ended questions asked clients if there was anything they found particularly helpful about the course, if there was anything that could be improved and what the main messages were that they were taking away with them. As so much data was collected immediately after the course, a basic thematic analysis was carried out on a ‘snapshot’ of the data to derive key themes.

Regarding what clients found particularly helpful, five themes emerged:

- the support received
- the content/sessions in general
- information on diet
- information on self-help techniques
- sharing with others/peer support
Results

“Feeling completely supported for the first time in a long time”

“Meeting others in the same circumstances. Trying new experiences”

“Talking to others and all the information about nutrition”

When asked if there was anything that could be improved, lots of useful data were received and four themes emerged:

• more on particular sessions e.g. diet/finance
• timings e.g. longer/shorter days
• structure e.g. more/less group work
• facilities/practical issues

“Perhaps more in depth on nutrition and family impact”

“Pace a little too slow. More work with peers”

“Comfier seats”

The final open-ended question regarding the main messages taken away, revealed six key themes:

• taking control/positivity
• taking time for/looking after self
• the Whole Person Approach
• self-help techniques/relaxation
• exercise
• diet

“That you, as an individual, can make an impact. You can take back control. Inspiring!”

“Make action plans and keep to it. Change way of eating. Exercise and live better. Reflect and have ME time. Look after oneself”

“Whole person model. Take care of the different dimensions”

Summary:
The Living Well course was well received and met clients’ needs and expectations.
Results

MYCaW – profile of reported concerns

MYCaW data is only reported for clients who provided follow-up data at 6 weeks (n=176).

Using the Qualitative Analysis Guidelines for MYCaW [10], the majority of first concerns (‘concern 1’) were identified as being psychological and emotional (59%). This was followed by physical concerns (16%) and concerns about wellbeing (14%) (Table 2).

Reported psychological and emotional concerns were primarily around family problems and relationships (35%), emotional problems (15%) and fear and anxiety (12%).

The majority of second concerns (‘concern 2’) were identified as psychological and emotional (44%), followed by concerns about wellbeing (24%) and physical concerns (20%) (Table 2).

Similar to concern 1, the most commonly reported concerns in the psychological and emotional category for concern 2 were around family problems and relationships (31%), emotional problems (14%) and psychological issues (11%).
### Results

#### Types of concerns reported

<table>
<thead>
<tr>
<th>Types of concerns reported</th>
<th>Concern 1</th>
<th>Concern 2</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological &amp; Emotional</td>
<td>59%</td>
<td>44%</td>
<td>“Emotional health – stress management – tendency to bottle things up while maintaining a calmer exterior”</td>
</tr>
<tr>
<td>Physical</td>
<td>16%</td>
<td>20%</td>
<td>“My cancer is in remission. My major worry is when is it going to come back?!”</td>
</tr>
<tr>
<td>Hospital/treatment</td>
<td>4%</td>
<td>5%</td>
<td>“How to cope with chemo side effects – restless, appetite, lethargy”</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>14%</td>
<td>24%</td>
<td>“How to change our diet for the best outcome. Objective being to have diet that makes you feel better and live healthily and longer”</td>
</tr>
<tr>
<td>Practical</td>
<td>7%</td>
<td>7%</td>
<td>“My future in employment and financial state”</td>
</tr>
</tbody>
</table>

Table 2. Profile of MYCaW concerns reported before the Living Well course
Results

MYCaW – Concern and wellbeing ratings

Baseline concern scores were fairly severe; 4.6/6 and 4.4/6 for concern 1 and concern 2 respectively, where 1 is the best and 6 is the worst. Using the same scale, the mean wellbeing rating was 3/6. **At the 6 week follow-up, there were statistically significant improvements in both concerns and wellbeing** (all p<.000), with ratings of 3.3/6, 3.1/6 and 2.3/6 for concern 1, concern 2 and wellbeing respectively (Chart 1).

The 6 week follow-up MYCaW asked if clients had any other things going on in their lives that were affecting their health. All data were coded according to the analysis guidelines for MYCaW. The majority of ‘other things’ reported (21%) were related to an ‘improved awareness of own wellbeing’, which includes positive lifestyle changes such as being more relaxed, taking more time for self, letting go of bad habits and changing priorities. Other frequently reported categories were ‘cancer related and negative’ (11%), which encompasses anything to do with the negative impact of cancer or its treatment, and ‘family problems’ (9%) which includes references to relationship problems or worrying about an ill relative.

The follow-up MYCaW also asked clients what the most important aspect was about the course they attended. Using the analysis guidelines, the two most commonly reported categories were the course sessions/content (37%) and ‘being with other visitors’ (32%). The third most commonly reported category was ‘relaxation and time for self/self-development’ (15%).

At the 12 month follow up, MYCaW data were received from 23 clients who had also completed their pre-course and 6 week follow-up MYCaWs. Although only a small number of clients, **MYCaW concern and wellbeing scores were still significantly improved at 12 months relative to baseline**; concern 1 p<.000, concern 2 p=.001, wellbeing p=.005. Friedman tests of all three time points (baseline, 6 weeks, 12 months) also confirmed that improvements were maintained over time for this small group; concern 1 p<.000, concern 2 p=.001, wellbeing p=.023.

**Summary**: The most commonly reported concerns expressed were psychological and emotional; MYCaW scores for concerns and wellbeing were significantly improved at 6 weeks and 12 months after the Living Well course.
Results

Health & Wellbeing Wheel

Full pre-course and 6 week follow-up data were received from 92 clients; a lower number of responses due to this questionnaire being introduced eight months into the project. Statistically significant improvements were found for all areas of the wheel (all \( p < .01 \)) except for ‘environment’, which remained stable at the 6 week follow-up.

Patient Activation Measure (PAM)

Full pre-course and 6 week follow-up data were received from 72 people; this measure was introduced nine months into the project from April 2015 to January 2016. For the whole cohort, there was a small but significant improvement in PAM scores at the 6 week follow-up (56.5 pre-course vs. 59.5 at 6 weeks, \( p < .05 \)), with 42% having a meaningful improvement (≥4 points) [29].

When change scores were stratified by baseline activation levels, the biggest changes were in those with the lowest levels of activation (levels 1 and 2). Clients who were at level 1 pre-course (n=14) had a mean score change of 10.5 (\( p = .003 \)), those who were at level 2 (n=22) had a mean change of 6.5 (\( p = .007 \)). Clients who were already at level 3 pre-course (n=33) were fairly stable with a mean change of -1.9, which was not significant (\( p > .05 \)). The number of clients at level 4 pre-course was too small (n=3) for meaningful analysis. A similar pattern in PAM scores emerged when looking at the proportion of clients who had a meaningful improvement relative to their baseline level; 71% at level 1 and 46% at level 2 had meaningful improvements, compared to 27% of those at level 3 (Figure 2). The number of clients at each level pre- and 6 weeks post-course were as follows; level 1 pre n=14, post n=6; level 2 pre n=22, post=21; level 3 pre n=33, post n=37; level 4 pre n=3, post n=8.

Summary:

PAM scores were significantly improved 6 weeks after the Living Well course. The biggest improvements were in clients starting at the lowest levels before the course (levels 1 and 2).

Figure 2. Percentage of clients at each level with a meaningful improvement in PAM score after the Living Well course. *Level 4 data added for completeness, only based on 3 people.
Results

6 week PREM – Lifestyle changes

The aim of the 6 week follow-up PREM was to explore clients’ reflections on the Living Well course after 6 weeks, to establish the key things that they had learnt and to see if this learning had translated into reported lifestyle changes or wider life changes since the course. Data were received from 209 clients.

Reflecting on specific changes made since the course; 84% said that the course had helped them improve their diet, 69% said it had helped them improve their level of exercise, 67% said it had helped improve their relationships, and 90% said it had helped improve their use of self-help techniques (Figure 3).

Reflecting on lifestyle changes overall, the majority (66%) reported that they had made ‘a few’ positive lifestyle changes since the course. Twenty one percent said they had made ‘lots’ of positive lifestyle changes, just 3% said they hadn’t made any changes. A small number (6%) said they weren’t sure how many changes they had made, and 3% said they needed more support from Penny Brohn UK to make positive lifestyle changes.
Results

6 week PREM – Barriers to lifestyle change

Qualitative data from our previous evaluation of the Living Well course [26] identified that clients experience many different challenges when it comes to making and sustaining lifestyle changes after the Living Well course. For the present evaluation, clients were asked which challenges they had come up against, to identify the key areas where they may need more advice or support. The most commonly reported challenges to lifestyle change were: side-effects of cancer treatment stopping them from exercising (20%), the weather putting them off exercising outside (16%), and finding unhealthy food comforting (15%) (Figure 4).

Summary:
The majority of Living Well course clients make some positive lifestyle changes. Some of the barriers they may face are treatment side-effects, bad weather and comfort of unhealthy foods.

Figure 4. Challenges faced by clients when trying to continue with healthy lifestyle changes
Results

6 week PREM – Additional resources and support

The Living Well course Handbook is integral to the course, providing concise summaries of the course content, links to research, space for writing SMART goals and information on further sources of support. Ninety seven percent of clients reported that they found the Handbook ‘very helpful’ or ‘helpful’ during the course, 85% continued to find the Handbook ‘very helpful’ or ‘helpful’ after the course.

All clients received a follow-up phone call from Penny Brohn UK’s Helpline four weeks after their course. The aim of the call was to see how clients were getting on and to see if they wanted to access any further support. Seventy six percent of clients found the phone call either ‘very helpful’ or ‘helpful’.

When asked what else they would have found helpful after the Living Well course, the most popular option was a DVD with cooking demonstrations or relaxation exercises, followed by an App with lifestyle tips. (Chart 2).

Chart 2. Other things clients would have liked from Penny Brohn UK after the Living Well course
Results

6 week PREM – Self-management

Six weeks after the Living Well course, 86% of clients reported that the course had enabled them to self-manage their health more effectively. An open-ended question asked clients to describe how the course had helped them to self-manage; four key themes emerged (Figure 5):

- diet
- exercise
- self-help techniques
- being given the knowledge, skills and confidence

“The connectedness of attitudes, emotions, diet and sleep and exercise are much more obvious now. I am empowered in a way I wasn’t”

“More confident over food, cooking, menus. Have discovered smoothies of fruit and yoghurt which I make everyday”

“I feel more well-informed now. The fear of having cancer has disappeared, and my control has taken over”

Figure 5. Key themes reported on how the Living Well course had helped people to self-manage their health
Results

6 week PREM – SMART goals reviewed

As part of the Living Well course, clients were facilitated to write SMART goals addressing six key areas of their life: health eating, physical activity, spirit, relationships and community, practical issues and environment, and mind and emotions. At the 6 week follow-up, clients were asked how happy they were with their progress against each goal. The lowest level of satisfaction was for physical activity (46%), which suggests that clients found this the most difficult area to make changes in (Figure 6).

6 week PREM – Wider life changes

Clients were asked about any other activities they had done as a result of attending the Living Well course. These activities included creative activities, self-help groups, exercise classes and other support. A wide range of activities were reported, with joining a meditation or self-help group (22%) coming top after ‘other’ (24%). This indicates that the Living Well course had a positive benefit beyond the confines of the course itself.

Figure 6. Percentage of people who are happy with their progress against the SMART goals they made on the Living Well course

Figure 7. Activities clients have done as a result of attending the Living Well course
Results

Additional open-ended questions asked clients if there was anything else in their lives that had changed as a result of the Living Well course. This question was asked to see if there were even wider benefits associated with attending the Living Well course. Thematic analysis of responses from this question yielded six key themes:

- using self-help techniques
- exercising
- diet changes
- being more open with others and relationship changes
- wider life and work changes
- feeling more positive and relaxed

“Changes in relationship – discussed with spouse the need for me to share the load of household chores/childcare”

“I have tried to keep my stress levels low at work by making sure that I finish work no later than 6pm. Previously I would work an average of 11 hours a day”

“Biggest change is my diet. Very pleased that I’ve adopted the 2/3 plant based approach. As a result people say I look well and I have lost some excess weight”

“I feel more independent and want to do more for myself and around the home. I want to travel and feel more positive about going away and not worrying about ‘what if something happens’. More relaxed and chilled in my everyday life.”
Results

A question regarding unexpected benefits of the course was also asked to see if people gained benefits from the course that they hadn’t anticipated. A thematic analysis revealed six key themes:

- peer support
- diet changes
- use of self-help techniques
- knowledge gained
- relaxation/time for self
- feeling more positive/confident

“Just being in an environment where you could just talk to people who were in a similar position”

“I have been able to give myself permission to slow down, to stop if I need to and to listen to my body rather than trying to be ‘normal’ me that others appeared to expect”

“I didn’t think that meditation was for me before the course but doing guided meditations on the course has encouraged me to use the CD from the course at home. Getting the exercise yesterday in my 8 week email was good – I like it and will use it.”

“Yes the food/diet was really informative. Have made some changes in our diet”

Summary: 6 weeks post Living Well course, the majority of clients perceived that it had helped them to self-manage their health; some people reported wider positive consequences and life changes triggered by the course.
Results

Living Well Course – KEY FINDINGS

• High levels of satisfaction were reported immediately after the course.
• Before the course, clients reported having mostly psychological and emotional concerns.
• Severity of concerns reduced and wellbeing significantly improved 6 weeks after the course.
• Concerns and wellbeing remained improved for clients who responded at 12 months.
• Patient Activation scores significantly improved 6 weeks after the course.
• The biggest improvements in Patient Activation were in those with the lowest levels before the course.
• The majority of clients reported making healthy lifestyle changes after the course.
• The majority of clients reported that they were self-managing their health more effectively as a result of the course.
Results

Follow-Up Support Evaluation Data

Follow-up support - Emails

All 519 clients attending the Living Well courses received a follow-up email 8 weeks after their Living Well course as well as a seasonal newsletter via email or by post. Feedback on the emails was sought via a short pop-up questionnaire and responses were received from 42 clients. The 8 week follow-up email included a message from Penny Brohn UK’s Lead Doctor, recipes, relaxation exercises and other hints and tips for health and wellbeing. The seasonal newsletters included further seasonal recipes, guided meditations, book reviews, information on self-massage techniques, walking and gardening for health, tackling sleep problems, ideas on how to increase physical activity and tips and links to developing mindfulness.

Ninety five percent of respondents said they found the content of the emails useful, 98% said they liked the layout, 95% felt that the emails had the right amount of information, and 95% felt that they had received the emails at the right time for them (Figure 8).

Follow-up support - Follow-Up Days

Demographic data showed that Follow-Up Day clients (n=120) were mostly people with cancer (83%), female (80%), White British (74%), with a mean age of 58.2 years (range 29 to 85 years). For people with cancer, the most common cancer site was breast (58%).

Data from the PREM administered at the end of the Follow–Up Day (n=90) showed that clients were highly satisfied with the service, with no aspect (including food, staff, resources and content) having a mean rating less than 4.4/5. In addition, clients rated the Follow-Up Days as 4.6/5 for meeting their needs and 4.7/5 for meeting their expectations. In addition, 89% of clients rated the pace as ‘just right’.

An additional open-ended question asked clients if there was anything they had found particularly helpful about the Follow-Up Day. Basic thematic analysis of the data revealed four key themes:

- sharing and meeting with others
- reminder of things learnt on the Living Well course
- feeling re-inspired and positive
- knowledge gained/the content of the day
Results

Felt they had received emails at the right time for them

95%

Found the content of the emails useful

95%

Liked the layout

98%

Felt they had received the right amount of information

95%

“Sharing experience with others. Getting re-inspired by the venue and the food and the Whole Person Approach”

“Reminding me of the aspects of wellbeing to re-focus my life”

“Revisiting ideas that had faded into the background of everyday life”

“More understanding and more positive to change myself”

Summary: Follow-Up emails and Follow-Up Days were well received and met clients’ needs. The Follow-Up services enabled reminders and reconnection to the previous experience of the Living Well course.
12 month longitudinal retrospective evaluation of the Wellness Package

A 12 month follow-up PREM was key to measuring the impact and clients’ experiences of the Wellness Package. Questionnaires were sent to a cohort of clients who attended Living Well courses between September 2014 and January 2015. Responses were received from 51 clients.

12 month PREM – lifestyle changes

Some questions were repeated from the 6 week follow-up questionnaire, to see if clients’ experiences or reflections were different after 12 months. Regarding lifestyle changes, the results were positive even after 12 months and very much mirror those collected at 6 weeks; 84% felt the Living Well course had helped them improve their diet, 67% felt it had improved their level of exercise, 68% felt it had improved their relationships, and 88% reported that the course had improved their use of self-help techniques (Figure 9).

Reflecting on the amount of lifestyle changes overall, 61% reported they had made ‘a few’ positive lifestyle changes as a result of the course, 28% reported they had made ‘lots’, only 2% reported making ‘none’, 8% were not sure and the final 2% reported needing more support from Penny Brohn UK to make positive lifestyle changes.

12 month PREM – Self-management

As at the 6 week follow-up, patients were asked if they felt the Living Well course had helped them self-manage their health more effectively. Reflecting back after 12 months, the majority (90%) again said ‘yes; the course had enabled them to self-manage their health. When asked how the course had helped them, the most popular answer was that the course had made them more knowledgeable about how to self-manage:
Results

- Made me more knowledgeable about how to improve my health (36%)
- Gave me the skills to make lifestyle changes (26%)
- Made me more confident to make lifestyle changes (23%)
- Other (8%)

12 month PREM – Practical support and wider life changes

To give a wider context to the results obtained, clients were asked whether the support from Penny Brohn UK had helped them practically with things like returning to work or other life responsibilities; 46% said yes, 18% said no, 36% said they did not know.

An additional open-ended question asked if anything else in their life had changed as a result of accessing the Living Well course and Follow-Up support, four key themes emerged:

- work changes
- improved support/relationships/communication
- lifestyle changes
- negative events/bereavement/unsupportive family

The final theme (negative events/bereavement/unsupportive family) was obviously not a result of accessing support at Penny Brohn UK, but for some clients, these events had shaped their experiences in the 12 months since the Living Well course.

“I understand my relationships better in light of my diagnosis”

“My marriage has broken down. Stress levels very high”

“Part-time at work then ill health retirement requested. Better attitude to my life and relationship with wife has improved”

“Now I look closely at what I eat and drink. Aware of need to increase my exercise but now use stairs at work instead of lift. Less breathless. Will use breathing technique to relax if stressed at work.”

Summary:
12 months after the Living Well course, and with additional Follow-Up support, the majority of clients reported that the Wellness Package supported them to self-manage their health. Some course participants reported wider positive life changes, for example returning to work.
Results

12 month PREM – Accessing Follow-Up support

Clients were asked about their access to Follow-Up support provided by Penny Brohn UK. In order to not overcomplicate the questionnaire for the clients, this referred to any Follow-Up support accessed, including further courses and one-to-one therapies offered at Penny Brohn UK’s National Centre, not just the Follow-Up support included in the scope of the Wellness Package.

Eleven of the responders at 12 months (22%) reported that they had not gone on to access any Follow-Up support from Penny Brohn UK after their Living Well course. An open ended question asked why this was the case and two key themes emerged; not needed/have other sources of support, and no time. Only one client reported that they did not enjoy the course.

“Got support from Macmillan nurse, hospital, family and GP”

“Because I have not had time due to family commitments”

“I feel that improving lifestyle has helped me sufficiently at the moment”

For those who had accessed Follow-Up support, the questionnaire asked them what difference they felt it had made (Chart 3). The most popular answer was that it had motivated them to carry on with healthy lifestyle changes. No one felt that the Follow-Up support had not made a difference.

If you have accessed follow-up support, what difference do you think it made?

[Chart 3. The difference Follow-Up support made to clients]
**Results**

12 month PREM – Accessing medical services

A key question on the 12 month PREM was whether clients (not including supporters) felt that the support they had received from Penny Brohn UK had changed the way they had accessed medical services over the past 12 months; **45% said yes**, 38% said no and 17% said they did not know (Figure 10).

For those who answered yes, an additional open-ended question asked how they felt this had been the case. Thematic analysis of responses from the 19 clients who answered this question derived two key themes:

- confidence to ask questions/make decisions /discuss care with doctors
- being more knowledgeable/aware

“I feel more able to be self-aware and listen to my body and therefore I don’t rush to the GP with every ache and pain”

“It has definitely meant that I visited GP less, I found PB gave me more agency to get through than NHS. And info. And support”

“Enable to be more confident when asking questions”

“Feel able to ask more knowledgeable questions”

“Not afraid to ask for help and know more about my condition”
Results

12 month PREM - Additional health information (not including supporters)

Additional questions were asked to establish a health profile of responders at 12 months. Questions duplicated those asked before the course and data were only analysed for clients who had complete data from both time points (n=27). This enabled comparison of health status at baseline and 12 months later.

For this small subgroup, the majority (54%) were undergoing active cancer treatment before the course. After 12 months, the majority had finished treatment within the last year (37%) or over a year ago (37%). Before the course, 60% of this group said they were living beyond cancer (no evidence of cancer in the body), after 12 months this figure had risen to 75%. Therefore, as a whole, the health status of this cohort had improved.

12 month PREM – Healthcare service use

Clients were asked to recollect their use of healthcare services at two time points; at the start of the course (for the last 3 months), and 12 months after the course (for the past 12 months). The 12 month figures were divided by four to give an indication of how often clients may have visited these healthcare providers in a 3 month period, allowing this data to be compared with the data collected before the course.

Retrospective reported use of healthcare services in the previous 3 months (n=27) indicated reduced numbers of average GP visits (1.4 vs 2.5 before the course), cancer team visits (1.3 vs 5.3 before the course), and other NHS services (1.5 vs 2.3 before the course).

It is important to note that this data is potentially biased as it is self-reported and its accuracy cannot be confirmed. However, the reduced number of reported visits to these healthcare providers by 12 months does map to clients’ improved health status by this time point.

Summary: A trend in the data suggests that healthcare usage decreased over the 12 months since the Living Well course. Clients also reported that the Wellness Package had changed the way they access medical services.
Results

The longer term impact of the Wellness Package – KEY FINDINGS

- Follow-up emails were reported to be useful, informative and timely.
- Follow-Up Days met clients’ needs and expectations.
- Follow-Up Days reminded people of things they had learnt on the Living Well course.
- Follow-Up Day clients reported feeling re-inspired and positive.
- After 12 months, the majority of clients still reported that the Living Well course had helped them make positive lifestyle changes.
- After 12 months, the majority of clients still reported that the Living Well course had helped them self-manage more effectively, mostly through making them more knowledgeable.
- For clients who accessed Follow-Up support, most reported that it had made a difference by motivating them to carry on with healthy lifestyle changes.
- At 12 months, no clients reported that the Follow-Up support had not made a difference.
The findings from this evaluation of Penny Brohn UK’s Wellness Package (Living Well Course and Follow-Up support) are that it was positively received, met clients’ needs and expectations, and had significant positive benefits in terms of self-management of health, health related quality of life and positive lifestyle change. Reconnections with the Living Well course content enabled by the Follow-Up support, gave clients the opportunity to refresh their knowledge and stay motivated with lifestyle changes. The wider aims and more specific objectives of this evaluation will now be reviewed.

The first aim of this evaluation was to measure the components of Penny Brohn UK’s Wellness Package; the established Living Well course and a new model of Follow-Up support comprising emails and Follow-Up Days. The longitudinal mixed-methods design sought to capture quantifiable outcomes and clients' lived experiences over the short and longer term. The results showed that the Wellness Package had a significant and positive impact on the majority of clients who took part in the evaluation. This positive impact was seen in the form of:

- improved concerns and wellbeing (MYCaW scores 6 weeks and 12 months post Living Well course),
- initiation of positive lifestyle changes (6 weeks and 12 months post Living Well course)
- improved self-management of health (PAM scores 6 weeks after the Living Well course)

The Follow-Up support motivated people to carry on with lifestyle changes and offered another opportunity to meet with peers. Reflecting on the impact of all the support they had received from Penny Brohn UK over 12 months, clients reported positive lifestyle changes, effective self-management of their health, practical changes such as returning to work and increased confidence around accessing medical services.

The second aim of the evaluation was to see how well the Wellness Package responded to the framework for survivorship set out by the NCSI in 2013 [27], particularly 1) promoting recovery and 2) sustaining recovery. The results indicate that the Living Well course addressed point 1 (promoting recovery), with clients leaving the course with the skills, knowledge and confidence needed to self-manage their health more effectively. The Living Well course along with the Follow-Up support addressed point 2 (sustaining recovery) as the data showed that the Follow-Up support helped people stay motivated with maintaining healthy lifestyle changes made after the Living Well course.
Discussion

In terms of the specific objectives of the evaluation, the success of each one will be considered in turn below:

A) Measure the impact of the Wellness Package on self-management: PAM scores were significantly improved, particularly for clients at the lower levels (1 and 2) pre-course, therefore those with the lowest scores have the most to gain from the course. When asked directly about whether the Living Well course enabled self-management of health, 86% of respondents said “yes” 6 weeks post Living Well course, and 90% agreed at 12 months. This evaluation provides good observational evidence that self-management is facilitated through the course content. However, it should be noted that it is not known what happened to those who did not respond to the evaluation; it is possible that only those engaged in self-management filled in the questionnaires. It may be useful to carry out qualitative research (with clients and course facilitators) to find out more about the mechanisms underpinning how self-management is enabled, and follow up those who do not engage in self-management of health.

B) Monitor if levels of wellbeing, cancer related concerns and lifestyle changes are supported and maintained over 12 months due to the combination of Living Well course and Follow-Up support provided: Overall, health related quality of life was significantly improved by the Wellness Package, and this was maintained over 12 months for those responding to the evaluation. MYCaW wellbeing scores and cancer related concerns were significantly improved 6 weeks and 12 months after the Living Well course. In addition, ratings of all areas (apart from environment) of the Health & Wellbeing Wheel were significantly improved 6 weeks after the Living Well course. In terms of lifestyle, the percentage of clients reporting positive changes was high (the lowest being 67% for exercise at 6 weeks and 67% for relationships at 12 months). However, this data should be treated with some caution as it came from clients’ self-reported perception of their own lifestyle changes; their actual behaviour may have been somewhat less idealistically positive.

C) Assess whether the Wellness Package has changed the amount of clients’ use of healthcare services: Research evidence shows that people living with cancer use GP services up to three times more than the general population [33]. Wellness Package clients’ own retrospective perceptions 12 months post course were that they used healthcare services less; 45% said the Wellness Package had changed the way they access healthcare services by increasing their knowledge and their confidence to talk to healthcare professionals. Emerging evidence shows a potential reduction in healthcare service use after accessing services in the Wellness Package. A reduction in self-reported healthcare service use was seen when healthcare service use before the Wellness Package (pre Living Well course) was compared to 12 months post Living Well course. Some clients also qualitatively reported visiting their GP less as a direct result of the support received. A potential cost saving of around £40 per GP visit [34] could be inferred from this data.

In addition, there were significant improvements in PAM scores and levels of activation. Previous research has shown that increases in activation are linked to reduced healthcare costs [29]. The data collected in the Wellness Package evaluation in terms of healthcare use and PAM levels is not robust enough to infer causation. Therefore, although these findings should be treated with caution, they can be seen as an interesting emerging trend where more research and evaluation is needed.
Discussion

Limitations of the evaluation

The design of this service evaluation does have some limitations. Firstly, the windows of data collection were cut short due to the reporting timescale. Secondly, although the response rate was good for a service evaluation (40% at 6 weeks, 28% at 12 months), the clients who did not respond to the questionnaires must be considered. The scope of this project did not allow for contacting ‘non-responders’ to find out their reasons, so it is possible that these clients did not have as good an experience as those who did respond, or did not feel that the services they accessed had an impact on them. However, ‘non-responders’ data collected on a previous evaluation of the Living Well course [26] showed that the main reasons for not responding were not to do with the course itself. Predominant reasons given were forgetting to fill in the questionnaires, being too busy or losing the questionnaires. It is hoped therefore, that the responses received for this project, do give an accurate picture of the impact of the services offered.

Due to the nature of the services provided, and the way multiple funding sources are used at Penny Brohn UK, it was not always possible to track the use of Follow-Up services and connect these to the clients using the Living Well course. The evaluation is therefore limited in not being able to contrast those who use the Living Well course with and without Follow-Up support. The evaluation instead presents an observation of clients’ experiences of the Wellness Package and pragmatically gathered as much data as possible.

Another limitation is that data on healthcare usage is self-reported. This project took some steps to try to gauge the health economic benefit of the Wellness Package, by looking at self-reported visits to NHS healthcare providers before the Living Well course and at the 12 month follow-up. The small amount of data received indicated reduced healthcare usage after 12 months. However, not only is this data self-reported, the difference may simply be due to the fact that most clients had finished their active cancer treatment after 12 months and were now living ‘beyond’ cancer. It is important to note however, that 45% of responders at 12 months said the support received from Penny Brohn UK had changed the way they accessed healthcare services, through making them more knowledgeable and confident. The qualitative data showed that for some people, this meant asking more focused questions in consultations, while for others it actually meant they visited their GP less as they felt more able to self-manage their health at home. The health economic aspect of the support offered by Penny Brohn UK is open for further investigation and vital to the long-term commissioning of services. More robust data collection using actual healthcare service use rather than self-reported retrospective use should be gathered in future evaluation and research.

A final limitation of this evaluation is that the data reported is for clients with cancer and supporters combined. There was not scope in this project for analysing the data separately, however the outcomes of the Living Well course for clients with cancer only have been published elsewhere [26]. Although the supporters’ data could be seen to have skewed the results due to them being a non-clinical population, the majority of clients (77%) were people with cancer. Further, previous evaluation that has looked at supporters’ data separately [25] found that the Living Well course was just as beneficial for supporters and that their MYCaW concerns were rated just as severely as clients with cancer. Previous research indicates how important it is that supporters of people with cancer also receive support [35-37].
The Wellness Package evaluation in a wider context

Since funding for this project was granted in 2014, several key documents have been published planning for the future of health and social care in the UK. The NHS Five Year Forward View [11] was published in October 2014 and set out a clear direction for change in the NHS. One of the key changes set out in the report is that the NHS will form better partnerships with voluntary organisations and with the help of these partners:

“…will invest significantly in evidence based approaches such as group-based education for people with specific conditions and self-management courses, as well as encouraging independent peer-to-peer communities to emerge.”

Through better partnership working with the voluntary sector and local communities, the Five Year Forward View recognises the role of people and communities in managing their own health and wellbeing. In response to this, in 2015 NHS England commissioned ‘Realising the Value’, a programme jointly led by Nesta and the Health Foundation, which aims to:

“…develop the field of person-centred, community-based approaches for health and wellbeing by building the evidence base at the same time as developing tools, resources and networks to support the spread and increase the impact of key approaches.” [38]

Building on the commitments set out in the Five Year Forward View, The Realising the Value programme identified five key approaches with the potential to improve the quality of life of people living with long-term conditions [38]:

1. Peer support
2. Self-management education
3. Health coaching
4. Group activities to support health and wellbeing
5. Asset-based approaches in a health and wellbeing context

In December 2015, Realising the Value selected a partner site to represent each of these approaches, with Penny Brohn UK selected as the partner site for self-management education. At the time of writing this report, Penny Brohn UK is working closely with the Realising the Value partners to develop practical toolkits to support the implementation of the five approaches identified. Evaluation data from Penny Brohn UK is also being fed into the design of an economic model to show the potential economic impact of these approaches, with this model then being used to develop a tool for commissioners to support their decision making. A final report with recommendations is due to be published by the Realising the Values partners in Autumn 2016.
Discussion

In April 2016, another key report from the Richmond Group of Charities [39] published evidence for the effectiveness of the Voluntary and Community Sector (VCS). In support of the Five Year Forward View, the report also set out recommendations for the VCS and the current health and social care system.

The potential is that the two sectors can work together more effectively, to “…support better outcomes for people and communities.” The report recommends that the VCS should collect meaningful data and clearly articulate how the evidence relates to the priorities of health and social care decision-makers.

“The voluntary and community sector (VCS) needs to make a strategic case for its inclusion in the design and delivery of the future health system.” [39]

Collectively, these reports demonstrate the need for transformation in the way health and social care services are delivered. With ever increasing financial pressures on the NHS, VCS organisations are being called on to show the measurable impact of what they do and clearly show how this meets the needs and priorities of statutory partners. With recognition from the health and social care system, VCS services can be woven into the fabric of a future health system that is far more sustainable than the current disease focused model.
Conclusion

The Wellness Package was positively received and met clients’ needs and expectations. The observational evaluation data showed a positive impact on self-management, health related quality of life and lifestyle changes. There is exciting evidence emerging of a potential reduction in healthcare service use as a result of the Wellness Package, and this positive trend warrants further investigation using more robust data collection methods. The Wellness Package has been successful according to the views of those who engaged in this evaluation.

The evidence gathered in this report meets the needs of the NCSI movement, and supports the values of wider health agendas such as the NHS Five Year Forward View and the Realising the Value programme. In this context, the results reported in this evaluation provide valuable insights into the impact of a self-management course and follow-up support for people with cancer and their supporters. Key reports published in the last 18 months demonstrate why it is crucial that Penny Brohn UK continues to provide an evidence base for its services through rigorous service evaluation. It is hoped that the results of this evaluation and Penny Brohn UK’s involvement in the Realising the Value programme, will alert commissioners to the huge potential for investing in self-management education, enabling more people to take control of their health and wellbeing and live as well as possible.
References

References


