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Moving Forward is a registered trademark for written information, training and educational services, and counselling and support services provided by Breast Cancer Care for people affected by breast cancer.

We thank HM Treasury and the Department of Health for the Tampon Tax Grant funding which allowed for this research and the scaling up of the Moving Forward course.

With thanks to Frontline Consultants and researchers from the University of the Highlands and Islands who undertook the research summarised within this evaluation.

Thank you also to Lurline, Cynthia, Debs, Caroline and Betty who feature in our photos.
At Breast Cancer Care we know that adapting to life after a diagnosis of and treatment for breast cancer can be extremely difficult.

Whether someone is experiencing side effects of treatment, wondering how to adopt a healthier lifestyle or experiencing the uncertainty and anxiety that can follow treatment for breast cancer, Breast Cancer Care’s Moving Forward course is there to support them.

Moving Forward provides information and support from experts on how to manage the concerns and side effects of breast cancer, and acts as a forum for people affected by breast cancer to share their experiences and support each other.

The research undertaken and presented in this report sought to evaluate and quantify the impact that Moving Forward has on participants, and to assess its economic value. We were delighted - but not surprised - to find that Moving Forward leads to significant improvements in quality of life, reduced levels of concern and increases ability and confidence to self-manage health, and that Moving Forward provides economic value to the NHS and wider society.

At Breast Cancer Care we warmly welcome the commitments made by the UK and devolved governments to support people to live well beyond cancer, and we are pleased to see progress being made through the implementation of the ‘Recovery Package’ in England and Wales and the ‘Transforming Care after Treatment’ programme in Scotland.

However, our findings point to the importance of people having access to tailored information, specific to the type of cancer they have. That’s why we are calling on the NHS to ensure that not only does everyone with breast cancer have access to evidence-based self-management support and information, but that it is tailored to them. The provision of information and support is a key component in both the ‘Recovery Package’ and the ‘Transforming Care after Treatment’ programme, and the NHS has an important role to play in promoting services like Moving Forward as a way of meeting these obligations.

To improve the lives of people following breast cancer and achieve world-class cancer outcomes, we must focus not only on immediate cure, but on how well someone is able to live after breast cancer. We must now ensure that everyone has access to the support and information they need after treatment, to enable them to adjust to life after breast cancer.
1. Introduction

1.1 Breast cancer in the UK

Breast cancer is the most common cancer in the UK, accounting for one third of female cancers and almost one sixth of all cancer diagnoses. Currently one in eight women in the UK will develop breast cancer in their lifetime, while around 390 men in the UK are diagnosed with the disease each year.

Earlier detection, increased understanding of the biology of the breast and substantial advancements in treatment have led to significantly improved survival rates. At present almost nine in ten women survive breast cancer for five years or more after diagnosis, and almost eight in ten survive for ten years or more.

1.2 The lasting effects of a primary breast cancer diagnosis

Improving survival rates are fantastic news for the thousands of people diagnosed with breast cancer every year. However, the need for support doesn’t end when treatment finishes.

People treated for breast cancer experience a number of unmet needs and ongoing concerns once their hospital-based treatment has finished.

Research undertaken by Breast Cancer Care in 2017 found that more than half of people diagnosed with primary breast cancer struggle with anxiety at the end of their treatment, and nearly a third with depression. Only 10% of people we asked felt positive and ready to move on when discharged from hospital treatment.

78% of cancer survivors report experiencing adverse effects of their disease and treatments within 12 months of their treatment finishing while 71% report experiencing at least one adverse effect more than ten years after treatment.

1.3 Supporting people beyond breast cancer: UK health policies

While historically cancer services have focused on cancer as an acute illness, with little support provided following the end of treatment, UK health policy now places significant emphasis on supporting people to live with and beyond cancer.

In July 2015 the cancer strategy for England, Achieving World-Class Cancer Outcomes: a strategy for England 2015–2020, was published. It includes specific commitments to ‘transform our approach to support people living with and beyond cancer’. The Cancer Delivery Plan for Wales 2016–2020 also recognises the need to ‘better meet the needs of people who have finished their treatment’. Both the English and Welsh cancer strategies included commitments to implement the ‘Recovery Package’.

The ‘Recovery Package’, developed through the National Cancer Survivorship Initiative in England, is a self-management package for people affected by cancer which has been shown to greatly improve the outcomes of care for cancer patients. It is comprised of four main interventions: a holistic needs assessment (HNA), a treatment summary, a cancer care review and access to a patient education (self-management) event. It is currently being rolled out in England and Wales.

The Scottish cancer strategy Beating Cancer: Ambition and Action also focuses on supporting people to live with and beyond cancer. The Transforming Care after Treatment (TCAT) programme, a collaboration between Macmillan Cancer Support and NHS Scotland, aims to provide tailored services and enable people to play a more active role in managing their own care. It is introducing, testing and evaluating new ways of doing this; including HNAs, end of treatment summaries and self-management groups.

1.4 Breast Cancer Care services

At Breast Cancer Care we want every person affected by breast cancer to get the treatment, information and support they need.

We have developed a range of services to help people to find a way to live with, through and beyond breast cancer. Our services provide information, offer emotional and practical support and bring people affected by breast cancer together.

The Moving Forward course is one of these services. Moving Forward was developed between 2008 and 2011, and rolled out from 2011 as a response to the many unmet needs that people experience after treatment for breast cancer.

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<table>
<thead>
<tr>
<th>Long term effects of breast cancer treatment</th>
</tr>
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<tbody>
<tr>
<td>• side effects of treatment:</td>
</tr>
<tr>
<td>- fatigue</td>
</tr>
<tr>
<td>- pain</td>
</tr>
<tr>
<td>- lymphoedema</td>
</tr>
<tr>
<td>• mental health problems:</td>
</tr>
<tr>
<td>- anxiety</td>
</tr>
<tr>
<td>- depression</td>
</tr>
<tr>
<td>• altered body image</td>
</tr>
<tr>
<td>• physical changes (e.g. weight gain)</td>
</tr>
<tr>
<td>• relationship, intimacy and fertility issues</td>
</tr>
<tr>
<td>• financial and employment concerns</td>
</tr>
</tbody>
</table>
We have undertaken extensive research to establish the impact of Moving Forward on participants. This report summarises the key findings. We would like to see the resulting recommendations put in place to ensure people are offered the care and support they need to enable them to live well after treatment for breast cancer.

2. Breast Cancer Care’s Moving Forward course

At Breast Cancer Care we know that many people find the end of hospital-based treatment for breast cancer difficult. It can be a time of uncertainty, fear and anxiety as people try to adjust to how they are feeling physically and emotionally after treatment.

In response to this, and acknowledging the unmet needs and long-term effects of a breast cancer diagnosis and treatment, we developed and tested Moving Forward between 2008 and 2011. Moving Forward is an adjustment focused self-management support model that aims to support and improve people’s recovery following treatment for breast cancer.

Designed in partnership with NHS healthcare professionals and service users and tested through a randomised research study, the course provides information and support from experts on how to manage the ongoing concerns and potential side effects of breast cancer and acts as a forum for people affected by breast cancer to share their experiences and concerns, and to support each other.

Breast Cancer Care’s Moving Forward courses are delivered in partnership with the NHS:

- Breast Cancer Care organises the courses, invites people affected by breast cancer to attend and facilitates the courses (through a trained facilitator engaged by and paid for by Breast Cancer Care, supported by a volunteer with a personal experience of breast cancer), and evaluates the sessions and provides reports to partners
- the NHS Trust/Health Board hosts the Moving Forward course, refers patients to the service and provides expert speakers to lead each session (typically a breast care nurse, dietician, physiotherapist or counsellor).

Currently Breast Cancer Care meets all the costs of organising, facilitating and evaluating Moving Forward courses; it is not a commissioned service.

2.1 Aims

The Moving Forward course aims to:

1. improve breast cancer patients’ self-confidence after treatment
2. empower patients with the knowledge and confidence to self-manage the physical, emotional and social effects of treatment
3. inform patients about where to access help and support in the future
4. reduce the isolation and emotional effects of breast cancer, through sharing experiences and coping strategies with their peers about the impact of breast cancer on their own and their families’ lives.

2.2 Structure

The course is delivered in sessions of three hours’ duration, taking place over three or four consecutive weeks. The sessions, which cover a range of topics, are delivered by expert speakers who provide practical information and emotional support.

<table>
<thead>
<tr>
<th>Example weekly programme</th>
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<tbody>
<tr>
<td>Each weekly session will be approximately 3 hours in total</td>
</tr>
<tr>
<td><strong>Week 1:</strong></td>
</tr>
<tr>
<td>- Introduction to the course</td>
</tr>
<tr>
<td>- Lymphoedema</td>
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<tr>
<td>- Menopausal symptoms</td>
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<tr>
<td><strong>Week 2:</strong></td>
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<tr>
<td>- Activity and energy</td>
</tr>
<tr>
<td>- Eating for health; dispelling the myths</td>
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<tr>
<td><strong>Week 3:</strong></td>
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<tr>
<td>- Breast and body awareness</td>
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<tr>
<td>- Cancer related fatigue</td>
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<tr>
<td><strong>Week 4:</strong></td>
</tr>
<tr>
<td>- Adjusting and adapting</td>
</tr>
<tr>
<td>- Complementary therapies</td>
</tr>
<tr>
<td>- Breast Cancer Care services</td>
</tr>
</tbody>
</table>
2.3 User feedback 2015

We asked people who had attended a Moving Forward course in 2015 how it had helped them. The results show that the courses are highly valued by participants. Attendance resulted in increased self-confidence, reduced social isolation and improved knowledge and understanding of how participants can live better with and beyond breast cancer.

**Self confidence**

Women said they felt more self-confident after attending a Moving Forward course.

‘I found it the most positive experience and I feel I've gained so much confidence.’

![45%](before.png)

**Before**

![91%](after.png)

**After**

**Knowledge and understanding**

Women said they had a better understanding of the side effects of breast cancer treatment after attending Moving Forward.

‘It addressed my feelings and fears and made me feel normal and less scared.’

![39%](before.png)

**Before**

![92%](after.png)

**After**

2.4 Where next?

In 2016/17 155 Moving Forward courses were delivered and 1,899 people attended. Whilst this represents significant growth since 2011 (when 37 courses were delivered and 281 people attended), we estimate that 62,000 people are diagnosed with breast cancer each year in the UK. This means Moving Forward is currently reaching less than 1 in 30 (3.1%) of the people who potentially need this type of support.

Moving Forward is a self-management course specific to breast cancer patients. It provides crucial elements of post-treatment care, information and support, and also covers self-management of ongoing side effects. Both of these elements are outlined in the Cancer Strategy for England as key components of the ‘Recovery Package’.

Breast Cancer Care is already working in partnership with NHS Trusts and Health Boards across the UK to deliver Moving Forward to breast cancer patients.

The continuation and expansion of this partnership approach would help meet the needs of more people living with and beyond breast cancer, by increasing our reach and access to Moving Forward. It would play a crucial role in supporting Cancer Alliances, Cancer Networks and Health Boards to implement the commitment to the ‘Recovery Package’ as well as the wider cancer strategies.

If Moving Forward is to support more people, it is necessary to provide detailed evidence of the benefits of a breast cancer specific health and wellbeing event and assess the impact on users of the course, as well as its economic value.
3. Methodology

To better understand the value and benefits of Moving Forward, Breast Cancer Care commissioned two independent pieces of research.

This section outlines the methodology used to evaluate Moving Forward. This has been separated into two parts.

While access to a health and wellbeing event is a key component of the ‘Recovery Package’, it is not specified whether these events should be cancer tumour site-specific (i.e. aimed at those with a specific type of cancer like breast cancer) or generic (i.e. for those with any type of cancer diagnosis). A rapid evidence review was undertaken to examine the evidence of self-management interventions, and to determine the effectiveness of site-specific interventions compared to generic interventions.

An economic evaluation of Moving Forward was undertaken by the research consultancy, Frontline Consultants. This consisted of two methodologies: self-reported data was collected by providing evaluation forms to Moving Forward participants with the purpose of measuring the impact of the course. The aim was to ascertain the difference it made to people experiencing physical, emotional and psychological concerns as a result of undergoing treatment for breast cancer. The self-reported data was subsequently used for the development of an economic model to evaluate the Social Return on Investment (SROI) of Moving Forward.

3.1 Rapid evidence review

Researchers from the University of the Highlands and Islands sought to describe and report the prevalence of long-term and late effects experienced by people at the end of primary treatment for the four most common adult-onset cancers in the UK: breast, bowel, prostate and lung cancer.

They did this by reviewing UK cancer charity websites, including Cancer Research UK, Macmillan Cancer Support, Breast Cancer Care, Bowel Cancer UK, Prostate Cancer UK and the Roy Castle Lung Cancer Foundation.

They also carried out a rapid evidence review of literature. This was based on literature available on the PubMed electronic database and published between January 2000 and July 2017.

Finally they reviewed existing post-treatment recovery, rehabilitation or self-management programmes in the UK, to ascertain the extent to which the identified effects of breast cancer diagnosis and treatments are covered in these programmes.

3.2 Economic evaluation

3.2.1 Self-reported data

A survey was produced to assess the impact that attending Moving Forward had on participants. It was distributed before (baseline) and after (follow-up) attending Moving Forward.

In total 873 baseline surveys and 552 follow-up surveys were completed between November 2016 and March 2017.

The survey collected information on five key areas, summarised below.

Quality of life

The EQ-5D is used widely within the context of chronic health conditions. It is a validated measure of health status and was used to evaluate the quality of life of an individual before and after attending Moving Forward. EQ-5D is currently being piloted by NHS England as a quality of life metric. It is also being used by NHS Wales as a metric to record Patient Reported Outcome Measures (PROMs). It is also used in Scotland to assess outcomes as part of the Improving the Cancer Journey (ICJ) project. This measure will be used to improve care and support for people following the end of treatment for cancer.

The metric requires respondents to rate their health in terms of mobility, self-care, daily activities, pain/discomfort and anxiety/depression on a scale from one to five. It provides a snapshot of an individual’s self-reported health at a given moment in time.

Health concerns

The Holistic Needs Assessment (HNA) is an assessment identifying the individual needs of a person affected by cancer. It enables people to recognise and report physical, practical, emotional, spiritual or social concerns. It was developed to ensure an individual’s needs are identified and appropriate measures taken to meet these. It is usually completed within the context of a health consultation at key milestones along the cancer pathway.

To assess the health concerns of participants before and after attending Moving Forward, the HNA was adapted to focus on the key concerns faced by people following treatment for breast cancer, as they adapt to their ‘new normal’ and are expected to become active self-managers of
their condition. These concerns were reviewed by a team of breast healthcare professionals and the Service Development Team at Breast Cancer Care. This process identified 22 key health issues/concerns and respondents were asked to rate the level of concern they experienced on a scale of one to ten.

**Patient activation**
NHS England defines patient activation as a description of ‘the knowledge, skills and confidence a person has in managing their own health and care’\(^\text{10}\). Evidence suggests that if people are enabled to self-manage their condition, their health outcomes will be better\(^\text{11}\). As Moving Forward is a self-management programme, it was important to assess how ‘activated’ participants felt as a result of attending the course.

Patient activation is recognised by NHS England in the Five Year Forward View\(^\text{12}\) as a central ambition for the NHS in England; empowering people to shape and manage their own health, and make informed decisions about their care. It requires an understanding of an individual’s level of engagement. The Patient Activation Measure (PAM) is a validated tool to measure this\(^\text{11}\). PAM requires respondents to rank statements relating to managing their health and care to measure their knowledge, skills and confidence in doing so.

**Demographic data**
Demographic data was collected to gather insight about the Moving Forward course participants.

**Attribution questions**
Attribution questions were used to understand the extent to which any changes in quality of life, healthcare needs and patient activation were considered to be a direct result of attending the Moving Forward course.

**3.2.2 Economic modelling: social return on investment**
To help demonstrate the impact of Moving Forward we also explored the social value of the course. The model of Social Return on Investment (SROI) was employed. The SROI tool is a well-recognised framework used by the Department of Health\(^\text{13}\), the Scottish Government\(^\text{14}\) and Public Health Wales\(^\text{15}\). It is a rigorous way of measuring the social value of a project or intervention. In our case the approach:

1. used results from the self-reported data to identify and quantify outcomes of attending the Moving Forward course
2. identified and used financial proxies to value the costs to society of not providing the outcomes that were provided through Moving Forward
3. calculated the SROI based on the cost of the course and the value to society of the course.
4 Findings

4.1. Rapid evidence review: the evidence for tumour site-specific courses

To best meet the needs of patients’ recovery and rehabilitation, programmes must vary by cancer tumour site\(^\text{16}\). The rapid evidence review found that some symptoms and side effects of cancer treatment are prominent across the four most common adult cancers. These side effects include infertility, fatigue and difficulty coping. However, there are others that are specific to the tumour type. The review compared the prevalence of long-term and late effects of cancer, by cancer tumour sites. The table below shows some of the key effects and prevalence of these effects by cancer type.

<table>
<thead>
<tr>
<th>Breast cancer</th>
<th>Prostate cancer</th>
<th>Lung cancer</th>
<th>Bowel cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue (5% to 38%)</td>
<td>Bowel problems (0% to 72%)</td>
<td>Pain (30%)</td>
<td>Bowel problems (38% to 62%)</td>
</tr>
<tr>
<td>Amenorrhea (absence of periods) (35% to 90%)</td>
<td>Hot flushes (50%)</td>
<td>Reduced pulmonary function (20%)</td>
<td>Sexual problems (28% to 44%)</td>
</tr>
<tr>
<td>Lymphoedema (15% to 49%)</td>
<td>Urinary problems (45%)</td>
<td>Recurrent disease (4% to 5%)</td>
<td></td>
</tr>
<tr>
<td>Anxiety (17.9% to 33.3%)</td>
<td>Sexual problems (42% to 87%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression (3% to 41.7%)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 1: Key effects and prevalence of effects by cancer type

The findings from the rapid evidence review point to different impacts of cancer, by cancer type. However, in reference to breast cancer, there is an extensive body of research findings that demonstrates the extent of unmet needs experienced by people following treatment.

Additional research findings have shown:

- **Fatigue** continues to be a problem many years after breast cancer treatment. Approximately 30% of patients experience persistent fatigue that lasts up to 10 years\(^\text{17}\).

- **Menopausal symptoms**, which are reported by the majority of women who receive treatment for breast cancer, have been found to negatively correlate with the quality of life of patients and their partners\(^\text{18}\). What’s more, most women experiencing hot flushes do not receive treatment due to lack of both awareness and confidence in the existing treatment options\(^\text{18}\).

- **Lymphoedema** remains a significant quality of life issue after treatment for breast cancer. Consequences including anxiety, frustration, sadness, anger, fear and increased self-consciousness impact a woman’s physical, psychological and emotional wellbeing\(^\text{19}\).

- Increased levels of **depression, anxiety or both** are apparent in the first year after a diagnosis of early breast cancer\(^\text{20}\).

- While the rapid evidence review did not include **fear of recurrence**\(^\text{21}\), this is an issue that affects between 60-99% of breast cancer survivors. It may be exacerbated once treatment is complete and can lead to increased use of healthcare services as individuals seek reassurance in distinguishing between recurrence and treatment-related body changes\(^\text{22}\).

The findings from the rapid evidence review, alongside the existing evidence outlined above,
point to a range of unmet needs experienced by people living with and beyond breast cancer. The combination of these unmet needs is unique to breast cancer.

As such, whilst generic self-management rehabilitation programmes can have all-inclusive content to address common effects, there is also a clear need for tumour site-specific content to enable people to manage the symptoms and side effects specific to their treatment and live well beyond cancer.

4.2 Economic evaluation: self-reported reduction of concerns

The research shows that Moving Forward improves emotional wellbeing and reduces the levels of concern experienced by people recovering from breast cancer.

‘The courses... covered a wide variety of concerns which gave me a lot of reassurance regarding having cancer.’

Whilst much is known about the issues/concerns that affect women after treatment for breast cancer, we evaluated the impact that Moving Forward has on these concerns.

Participants were asked to rate from 1 to 10 (1 being ‘not a concern’; 2-4 being ‘some concern’; 5-7 being ‘significant concern’; and 8-10 being ‘major concern’) the extent of their concern from a list of 22 issues that were identified as most pertinent to breast cancer patients. The issues they were asked to rate are listed below:

1. Anxiety, fear or worry
2. Fear of recurrence
3. Exercise and activity
4. Fatigue
5. Low mood
6. Menopausal symptoms
7. Relationships
8. Fertility
9. Depression
10. Body image
11. Feeling isolated and lonely
12. Memory loss
13. Bone health/osteoporosis
14. Employment
15. Social support
16. Sleep
17. Aches and pains
18. Nutrition and eating well
19. Sexual or intimacy issues
20. Knowing what support services are available
21. Lymphoedema
22. Prostheses

The results show that Moving Forward reduced the number of participants noting a concern (rated from 2-10) across all areas. Table 2 below shows the biggest reduction between baseline and follow-up.

1. The number of people who reported knowing what information and support is available as a concern decreased by over 40% after taking part in Moving Forward
2. The number of people who reported depression as a concern decreased by 18% after taking part in Moving Forward
3. The number of people who reported exercise and activity as a concern decreased by 14% after taking part in Moving Forward.

<table>
<thead>
<tr>
<th>Concern</th>
<th>Baseline</th>
<th>Follow-up</th>
<th>Reduction in number of people noting a concern</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowing what support is available</td>
<td>51% (433)</td>
<td>29% (157)</td>
<td>43%</td>
</tr>
<tr>
<td>Depression</td>
<td>57% (477)</td>
<td>47% (254)</td>
<td>18%</td>
</tr>
<tr>
<td>Exercise and activity</td>
<td>71% (601)</td>
<td>61% (333)</td>
<td>14%</td>
</tr>
</tbody>
</table>

Table 2: Participants noting a concern

As well as reducing the percentage of people experiencing each concern, Moving Forward also had a positive impact on reducing the severity of concerns that were noted as either ‘significant’ or ‘major’, i.e. if a concern was given a score of 5-10 by participants. Table 3 below shows the largest areas of impact.

1. The number of people who reported menopausal symptoms as a significant or major concern decreased by a third after taking part in Moving Forward
2. The number of people who reported sexual or intimacy issues as a significant or major concern decreased by 39% after taking part in Moving Forward
3. The number of people who reported exercise and activity as a significant or major concern decreased by almost half after taking part in Moving Forward
4. The number of people who reported nutrition and eating as a significant or major concern decreased by 44% after taking part in Moving Forward.
It was also possible to analyse changes in the average score for each concern from baseline and follow-up. While there was a reduction from baseline to follow-up across all concerns, Table 4 below shows the changes in average score for those starting with the highest level of concern.

<table>
<thead>
<tr>
<th>Concern</th>
<th>Baseline Average Score</th>
<th>Follow-up Average Score</th>
<th>Reduction in Average Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Menopausal symptoms</td>
<td>48% (247)</td>
<td>32% (106)</td>
<td>33%</td>
</tr>
<tr>
<td>Sexual or intimacy issues</td>
<td>41% (161)</td>
<td>25% (57)</td>
<td>39%</td>
</tr>
<tr>
<td>Exercise and activity</td>
<td>31% (189)</td>
<td>17% (56)</td>
<td>48%</td>
</tr>
<tr>
<td>Nutrition and eating well</td>
<td>34% (145)</td>
<td>19% (43)</td>
<td>44%</td>
</tr>
</tbody>
</table>

Table 3: Participants noting a significant of major concern

The findings relating to exercise and diet are very positive. A growing body of evidence cites the benefits of exercise for those who have had breast cancer treatment. Physical activity has the most robust effect of all lifestyle factors on reducing the risk of breast cancer recurrence making exercise an undeniably important intervention. Yet studies show women tend to decrease levels of activity after their diagnosis and few attain the recommended amounts of exercise each week.

A 2016 review also showed that dietary modification and increased exercise can reduce the risk of recurrence and mortality in breast cancer survivors. It can help to avoid or reduce some side effects of cancer treatment, such as fatigue, weight gain, osteoporosis and lymphoedema.

Our results show that Moving Forward crucially reduces levels of concern relating to diet and exercise. Moving Forward provides breast cancer specific information about being active and eating a healthy diet to enable people to make lifestyle changes that could meaningfully contribute to their chances of surviving breast cancer.

Fear of recurrence was the highest noted concern (both at baseline and follow-up) and also saw one of the greatest reductions in level of concern from baseline to follow-up. Educating people to recognise the signs and symptoms of recurrence could mean that people feel empowered and informed to self-manage their condition. This in turn may positively impact their mental health, reduce anxiety and improve quality of life.

Better knowledge about the signs and symptoms of recurrence could also mean that patients are more likely to report concerns and are therefore better able to get back into the healthcare system more readily.
4.3: Quality of life
Our research shows that Moving Forward significantly improves quality of life of participants.

The negative impact of a diagnosis of and treatment for breast cancer on quality of life is well known and it is something we are often told about by clients who access our services.

‘[I] always have the fear of cancer returning.’

‘I am having so many problems with side effects from hormone treatment.’

Research also shows that self-management programmes focused on education and information can improve quality of life following breast cancer treatment. This is supported by our findings.

The average EQ-5D score for female members of the general population is 0.85. This number is considered an indicator of ‘normal’ quality of life.

Prior to attending Moving Forward, respondents had an average score of around 0.79 on the EQ-5D metric for quality of life.

On completion of the Moving Forward course, the quality of life score of participants had risen to around 0.83.

This means that people were moved from below average quality of life to a near normal quality of life after attending the Moving Forward course. This is a significant achievement given that those attending Moving Forward had all been diagnosed and treated for breast cancer.

Of our sample, 59% reported continued improvements in their quality of life one month after attending the course. Of this sample, 90% reported that these improvements were a direct result of attending Moving Forward.

How does Moving Forward compare to other interventions?
Whilst this is one of the first studies to evaluate a survivorship intervention for cancer patients using EQ-5D, a 2014 study reviewed interventions for a range of health concerns.

The 0.04 increase recorded for Moving Forward participants is within the range that a patient would identify as significant.

4.4 Patient activation
The Moving Forward course empowers and enables people to become ‘active self-managers’ of their own health and wellbeing.

‘This course and those facilitating it gave me the confidence, as well as the skills, to enable me to move forward. I feel more relaxed and can get on with living my life. I’m now aware of what I need to do if I have any problems in the future.’

The Patient Activation Measure (PAM) separates individuals into one of four activation levels (see figure 1) derived from a PAM score calculated after the completion of a survey. Each level provides insight into health-related characteristics, including attitudes, motivators and behaviours, which determine the ability to self-manage one’s health and healthcare. It has been suggested that higher activation levels could correlate to better adherence to treatment regimes, as well as patients seeking preventive care, engaging in healthy behaviours and seeking out and using health information.

Figure 1: Patient activation levels

Adopting behaviours needed to support health: individuals may still struggle in times of stress or change

Taking Action: individuals have the key facts and are building self management skills

Becoming aware, but still struggling: individuals have some knowledge, but large gaps remains. They often believe their health is outside their control

Disengaged and overwhelmed: individuals are passive and lack confidence
Given that cancer survivors are increasingly expected to self-manage the consequences of cancer and its treatment and that self-confidence is important for successful self-management\(^3\), it is promising that our results show that Moving Forward has a positive impact on activation levels.

Table 5 below indicates the percentage of respondents who fell into each activation level before and after attending Moving Forward. The results show that just under a third (28%) of patients join the Moving Forward course at level 2, indicating that they were ‘becoming aware, but still struggling’, believing that their health is ‘outside of their control’. However, after attending Moving Forward an additional 10% of people were moved into level 4, the highest activation level. This means that they have ‘adopted behaviours needed to support health’. This suggests that Moving Forward increases self-confidence and enables people to adopt behaviours which support their health and improve outcomes.

<table>
<thead>
<tr>
<th>Level</th>
<th>Before</th>
<th>After</th>
<th>Percentage change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>7%</td>
<td>7%</td>
<td>0%</td>
</tr>
<tr>
<td>2</td>
<td>28%</td>
<td>18%</td>
<td>10% decrease</td>
</tr>
<tr>
<td>3</td>
<td>51%</td>
<td>51%</td>
<td>0%</td>
</tr>
<tr>
<td>4</td>
<td>14%</td>
<td>24%</td>
<td>10% increase</td>
</tr>
</tbody>
</table>

Table 5: Changes in activation level

There is also a clear correlation between increased patient activation and a reduction in level of concern felt by patients. The graph below shows the correlation between PAM and fear of recurrence. It shows that as activation levels increase, fear of recurrence is reduced.

The correlation between a lower level of concern and higher levels of activation is apparent for all 22 health concerns listed in section 4.2. This suggests that as an individual becomes more confident, they are better equipped to manage their concerns and as a result the extent of their concern decreases.
4.5 Social return on investment
Moving Forward provides significant social returns on investment. Calculations show for every £1 spent by Breast Cancer Care the value to society is equal to £4.50.

The evaluation identified the positive impact that Moving Forward has on people in the following ways:

- improving the mental wellbeing of people treated for breast cancer, and also benefitting their family and friends
- improving the physical wellbeing of people treated for breast cancer
- reducing a number of concerns, and reducing level of concern(s), across 22 known symptoms and side effects/issues for people after breast cancer treatment
- increasing self-confidence
- improving lifestyle, particularly health and exercise
- improving quality of life.

The model attached identified costs (or financial proxies) to the level of improvements in each of these outcomes, to calculate a potential theoretical Social Return on Investment (SROI) ratio of £1:£4.50.

This means that for every £1 invested by Breast Cancer Care to deliver Moving Forward, the value to wider society is valued at £4.50.

The value of a Moving Forward course far outweighs its cost. It results in positive outcomes for people and society as a whole.

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Lurline Thomas, 54, was diagnosed with breast cancer in 2016 and attended the North London Moving Forward course at Mount Vernon Cancer Centre.

‘I was diagnosed with breast cancer in March 2016 after attending a routine mammogram. It was a complete shock – I was fit and healthy with no symptoms at all.

‘The diagnosis has completely changed my life. I now have long-term side effects, including fatigue, joint pains, lymphoedema and heart problems, which mean I still haven’t been able to return to work.

‘Other people assume you’re back to normal once you finish treatment. But this isn’t the case. Moving Forward reassured me I wasn’t the only one struggling to adjust and showed me recovery is a gradual process, which varies from person to person.

‘The course has helped me adapt to my new reality. I was taught coping mechanisms, received expert advice and shared my experience with other people who had been through similar things.

‘Even though my life has changed, I now see this as having opportunities and not obstacles. Along with my faith, family and friends, the Moving Forward course helped me to be very grateful for life, to be adaptable and have hope for the future.’
5. Conclusion and recommendations

The evidence presented in this report provides valuable insight into the importance of tumour site-specific cancer support interventions. It also supports existing research into the concerns of people following treatment for breast cancer and provides evidence into the extent to which Breast Cancer Care’s Moving Forward course addresses these concerns. Our research found that:

- side effects, long-term effects and late effects vary by cancer tumour site. As such, patients with breast cancer should have access to a breast cancer specific course following treatment
- Moving Forward significantly improves quality of life of participants
- the concerns of participants are reduced and emotional wellbeing is improved following attendance of Moving Forward
- Moving Forward increases activation levels of participants, empowering and enabling people to be self-managers of their own health and wellbeing
- Moving Forward offers real value to women who have experienced breast cancer, and to society

Impact on the individual

The results from this evaluation corroborate existing research about the variety of complex physical, social and emotional needs that people with breast cancer experience as they move forward after treatment. It also shows that Moving Forward is meeting many of these needs.

The evaluation, which has utilised metrics including PAM and EQ-5D, has provided strong and robust evidence which point to the benefits of the Moving Forward course.

The findings show that individuals become more engaged or ‘activated’ after attending Moving Forward. This correlates with significantly reduced levels of concern, most notably reduced depression, improved emotional wellbeing and reduced concerns relating to diet and exercise.

This is supported by the EQ-5D measure, which shows significant improvements in quality of life from baseline to follow-up after attending the Moving Forward course. Improvements in quality of life can lead to increased efficacy and confidence to make health-related lifestyle changes. This in turn could improve overall wellbeing and emotional, physical and mental functioning through breast cancer recovery and survivorship.

Given the adoption of the EQ-5D metric by NHS England and its use by NHS Wales and in Scotland, we would expect this finding, in particular, to carry significant weight with not only NHS England, NHS Scotland and NHS Wales but with commissioners, healthcare planners and providers.

Impact on society and the NHS

As well as benefits to the individual, the results of our evaluation show clear opportunities for society and the NHS.

For every £1 invested by Breast Cancer Care to deliver Moving Forward, the theoretical value to wider society is £4.50.

There are also clear potential benefits to the NHS. People at higher levels of activation experience better health, have better health outcomes and fewer episodes of emergency care. Each point increase in PAM score correlates with a 2% decrease in hospitalisation and a 2% increase in medication adherence.

Moving Forward results in increased activation levels of participants. At present Moving Forward is reaching just 3.1% of people following a breast cancer diagnosis. Expansion of the course would not only provide crucial support to individuals, but it would offer clear opportunities to reduce pressure on the NHS.

What does this mean for the Moving Forward course?

The results from our evaluation point to the necessity for comprehensive tailored support, through cancer site-specific rehabilitation programmes, to support people to successfully self-manage the ongoing effects of breast cancer diagnosis and treatment. They also highlight the impact that Moving Forward, as a tumour site-specific course, has on the individual, the NHS and on wider society.

At Breast Cancer Care we recognise that self-management courses may not be appropriate for everyone and that it may not always be possible for people to attend a number of sessions over a number of weeks. In response to this, we also offer a comprehensive Moving Forward Resource...
Pack and have developed the BECCA breast cancer support app, which are available alongside our other services such as our Helpline, Someone Like Me service and online support through the Breast Cancer Care Forum.

However, given the strength of evidence, there is a clear case for the expansion of the course to support more people through the delivery of Moving Forward and for the NHS to ensure that this type of tailored intervention is established as part of the pathway for breast cancer patients.

**What are we calling for?**

The Cancer Strategies for England, Scotland and Wales all point to the need to better support people following treatment for cancer.

In England and Wales this commitment is being implemented through the roll-out of the ‘Recovery Package’. In Scotland the Transforming Care after Treatment (TCAT) programme is changing the way that follow-up and post treatment care is managed with the emphasis on risk stratified person centred follow up.

The ‘Recovery Package’ makes specific reference to patients having access to a health and wellbeing event to provide information and support, with the aim of patients having better understanding and more confidence in managing their health. It does not, however, specify whether these courses should be tumour site-specific or generic.

Given the findings of our rapid evidence review, which point to the specific side effects of breast cancer treatment that differ considerably from the side effects of the other most common cancers in the UK, we recommend that patients with breast cancer are offered breast cancer specific interventions. When we asked our sample what type of course they thought would best meet their needs – a course that is specific to breast cancer or a course for all types of cancer – 96% said a breast cancer specific course. It is also worth noting that breast cancer patients represent the largest cancer patient group in the UK, with approximately 691,000 people living after a breast cancer diagnosis. Cases of newly diagnosed breast cancer are also increasing year on year. As such, there is a strong case, as well as a growing need, to provide specific breast cancer health and wellbeing events for this patient group.

Moving Forward is a self-management patient education service specific to people treated for breast cancer. It provides crucial elements of post-treatment care and support. This includes access to a patient education support event and information on managing side effects of treatment, both of which are recognised as crucial parts of health policy.

Our findings show that Moving Forward improves quality of life, reduces concerns and activates participants to self-manage their healthcare. In light of this we recommend the NHS across the UK promotes Moving Forward as an evidence-based self-management programme for breast cancer patients.

Breast Cancer Care is already working in partnership with NHS Trusts and Health Boards in England, Scotland and Wales to deliver Moving Forward. Further expansion in the provision of this course would not only help meet the needs of more breast cancer patients, it would provide a ‘ready-made’ solution to support NHS organisations to meet their obligations and play a crucial role in the delivery of the Cancer Strategies.

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**Breast Cancer Care’s recommendations**

1. The NHS should ensure every breast cancer patient has access to a health and wellbeing event that meets the criteria outlined in the respective cancer strategies, such as Moving Forward, once their hospital treatment ends.

2. Health and wellbeing events for breast cancer patients must be breast cancer specific so that they are tailored to meet patients’ needs and have maximum impact on their ability to live well after a diagnosis of and treatment for breast cancer.

3. Health and wellbeing events are a key component of the ‘Recovery Package’ in England and Wales, and the Transforming Care after Treatment programme in Scotland. The NHS should promote evidence-based interventions, such as Moving Forward, to Cancer Alliances and Networks, Hospital Trusts and Health Boards, and recommend these events as a way to meet the requirements of the ‘Recovery Package’ and the Transforming Care after Treatment programme.
6. References


3. Figures from a Breast Cancer Care survey. Fieldwork was undertaken online between 13 April and 31 May 2017. Total sample size: 804 women, who had had a primary diagnosis of breast cancer


11. The Kings Fund, Supporting people to manage their health, an introduction to patient activation, 2014


13. Department of Health, Measuring social value: how five social enterprises did it, 2009


23 J. Harmer, E. Warner. Lifestyle modifications for patients with breast cancer to improve prognosis and optimize overall health. Canadian Medical Association Journal. Published online 21 February 2017

24 M. Irwin et al. Physical activity levels before and after a diagnosis of breast carcinoma, Cancer, 97:7, 2003

25 C. Dieli-Conwright, L. Wong, S. Waliany, L. Bernstein, B. Salehian, J.E. Mortimer. An observational study to examine changes in metabolic syndrome components in patients with breast cancer receiving neoadjuvant or adjuvant chemotherapy, Cancer. 122:17, 2016


30 The Rich Picture with Cancer, Macmillan Cancer Support, 2014

31 Newly diagnosed case have increased in:

- **England**: from 33,000 new cases in 1995 to 53,000 in 2015: ONS, Cancer Registration Statistics, England, Table 10. Includes Carcinoma in situ of breast and Malignant neoplasm of breast


- **Wales**: from 2,176 new cases in 2001 to 2,802 in 2015: WCISU, Cancer Incidence in Wales: Dashboard & Data
When you have breast cancer, everything changes. At Breast Cancer Care, we understand the emotions, challenges and decisions you face every day, and we know that everyone’s experience is different.

For breast cancer care, support and information, call us free on 0808 800 6000 or visit breastcancercare.org.uk

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