

*Macmillan Cancer  
Support -  
Evaluation of the  
Transforming  
Cancer Follow-up  
Programme in  
Northern Ireland  
Final Report*

February 2015

*Final Report*

# Acknowledgements

The PwC evaluators are grateful to all those who have contributed to this work. We would like to thank those in Macmillan Cancer Support (Macmillan) and Northern Ireland Cancer Network (NICaN) for their support, and also the Evaluation Advisory Group (EAG) members for their advice and guidance.

In particular, we value the contributions of the Transforming Cancer Follow-Up (TCFU) Project Managers in each Trust for their help and support throughout this evaluation.

We would also like to thank Trust staff who participated in focus groups and interviews, and everyone who has participated in interviews, including the project team, GPs, and Voluntary and Community groups.

Finally, and most importantly, we would like to thank the patients who gave up their free time to contribute to the patient survey, and the focus groups; without their contribution this evaluation would not have been complete.



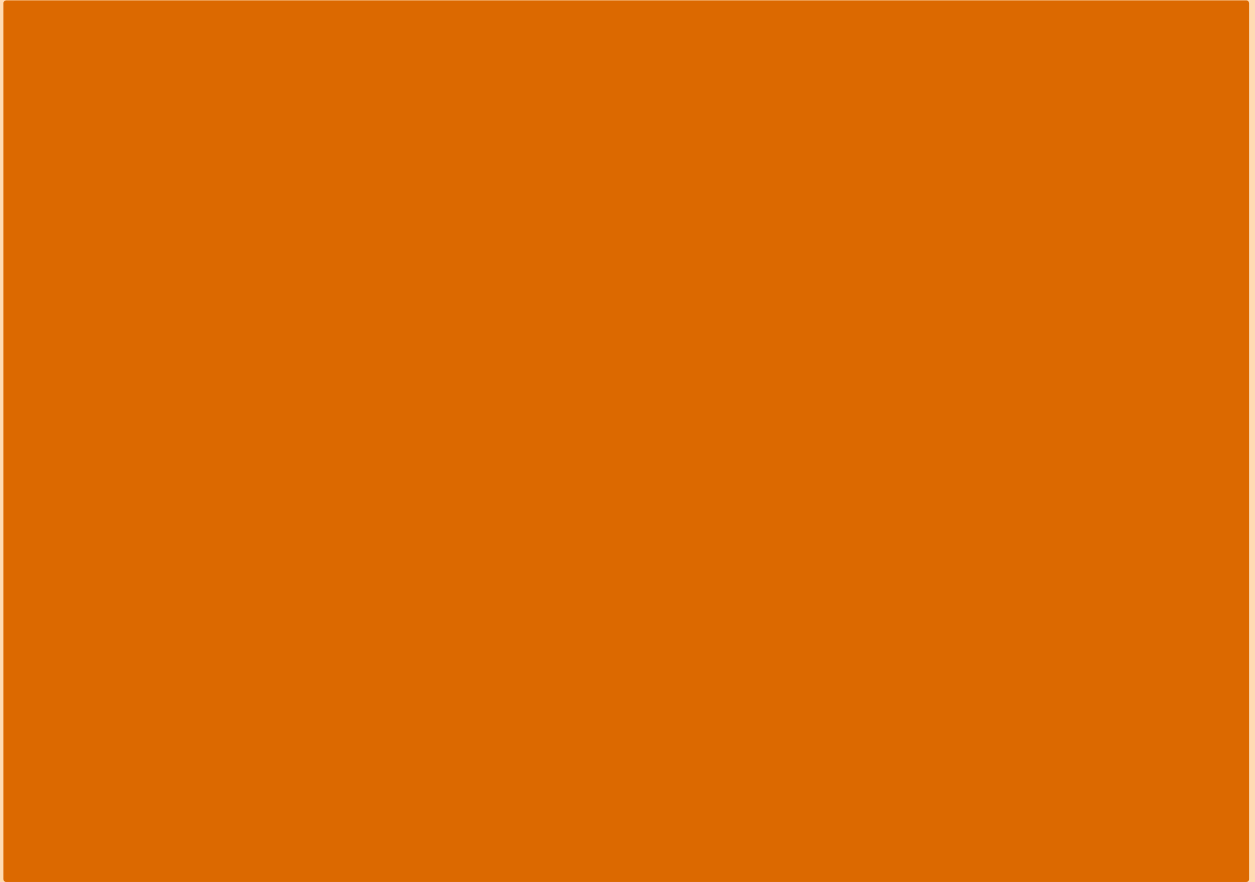
# Glossary

<b>Abbreviations</b>	<b>Definition</b>
NI	Northern Ireland
TCFU	Transforming Cancer Follow-up
TYC	Transforming Your Care
HSCB	Health and Social Care Board
PHA	Public Health Agency
NICaN	The Northern Ireland Cancer Network
EAG	Evaluation Advisory Group
NRES	National Research Ethics Services
SDA	Self-Directed Aftercare
HNA	Holistic Needs Assessment
TSR	Treatment Summary Record
PSA	Prostate Specific Antigen
RISOH	Regional Information System for Oncology and Haematology
HSC	Health and Social Care
CNS	Clinical Nurse Specialist
PAS	Patient Administration System
LCG	Local Commissioning Groups

# Contents

<b>1. Introduction.....</b>	<b>5</b>
<i>Background to TCFU</i>	6
<i>Background to the evaluation</i>	11
<i>Methodology</i>	12
<b>2. Improving cancer patients aftercare experience .....</b>	<b>15</b>
<i>Introduction</i>	16
<i>Progress</i>	17
<i>Impact</i>	19
<i>Challenges</i>	25
<i>Summary and conclusions</i>	27
<b>3. Improving resource utilisation .....</b>	<b>28</b>
<i>Introduction</i>	29
<i>Progress</i>	29
<i>Impact</i>	31
<i>Challenges</i>	32
<i>Summary and conclusion</i>	34
<b>4. Enhancing the coordination and integration of care.....</b>	<b>35</b>
<i>Introduction</i>	36
<i>Progress</i>	36
<i>Impact</i>	37
<i>Challenges</i>	38
<i>Summary and conclusions</i>	39
<b>5. Learning from the programme.....</b>	<b>40</b>
<i>Introduction</i>	41
<i>What has worked well?</i>	41
<i>What could have worked better?</i>	43
<i>Is TCFU transferable?</i>	44
<i>Is TCFU sustainable?</i>	45
<i>Summary and conclusions</i>	46
<b>6. Areas for consideration .....</b>	<b>47</b>
<b>7. Appendices.....</b>	

# ***1. Introduction***



## **Background to TCFU**

### **The need for TCFU**

Living With and Beyond Cancer<sup>1</sup> provides the first ever detailed picture of cancer prevalence in Northern Ireland (NI), which is defined as the number of living people who have had a cancer diagnosis. Almost 70,000 people in NI are living with cancer, or have had a cancer diagnosis in the last 18 years, and there has been an annual 3.5% rise in the numbers living with cancer in NI since 1993. Improvements in survival related to treatment advances and screening, and also reductions in the number of deaths from other diseases such as heart disease, have contributed to the increase in the number of cancer survivors. If current trends continue, by 2030 there could be over four million cancer survivors in the UK; with breast, prostate and colorectal accounting for over half.

Until recently, cancer has been viewed in simple terms; either people are cured and get back to normal or else they will have terminal cancer and die. However the cancer landscape is changing and the picture emerging is a more complex one. While some still die within a year of diagnosis, advances in treatment mean that those with incurable cancer can live for years and experience similar illness patterns to those with long-term conditions, with many suffering from complex co-morbidities<sup>2</sup>, and people who fully recover from cancer can still suffer from co-morbidities. In addition, there are wider implications for patients diagnosed with cancer, beyond their clinical needs, as a cancer diagnosis can impact patients on a physical, practical, financial and emotional level.

These changes have led to a growing recognition that current models of cancer follow-up are not as effective as they could be, and with increasing numbers of cancer survivors there is increasing pressure and demand on the current healthcare system. In a review of the evidence in relation to the aftercare provided for people with breast cancer<sup>3</sup>, it was reported that there was widespread variation in cancer follow-up practice with no consensus as to the intensity, duration or type of follow-up required. Follow-up appointments often do not meet the patients' needs.<sup>4</sup> In addition, women receiving breast cancer follow-up services have reported that the increasing gap in their six monthly review appointments has led to concern and worry,<sup>5</sup> leading to interference in returning to everyday life.<sup>6</sup>

### **The TCFU timeline**

At a Northern Ireland Cancer Network (NICaN) workshop during 2009 for patients and carers, a key message heard was the need to radically improve aftercare services. In April 2010 professionals echoed this at a second NICaN workshop. In his opening remarks Chief Medical Officer, Dr Michael McBride stated, *"We need to move away from the current model of follow-up which focuses solely on physical symptoms and illness, to one that focuses on health and well-being. This requires flexible, accessible, risk based follow-up models... personalised to the individuals' needs, with the patient a key contributor to setting goals and agreeing plans."*

In June 2011, the Minister for Health, Social Services and Public Safety (DHSSPS) in NI announced that a review of the provision of health and social care services in NI would be undertaken. In December 2011, the DHSSPS published "Transforming Your Care: A Review of Health and Social Care in Northern Ireland". The Transforming Your Care (TYC) Review proposed a new model of care for NI, underpinned by twelve major principles for change. These principles underpin the TCFU programme, in particular the programme places the

<sup>1</sup>Department of Health, Macmillan Cancer Support and NHS Improvement. (May 2013) *Living with and beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision)*. <http://www.ncsi.org.uk/wp-content/uploads/Living-with-and-beyond-2013.pdf>. (Accessed 12<sup>th</sup> January 2015)

<http://www.qub.ac.uk/research/centres/nier/FileStore/PDF/Incidence/Filetoupload,382846,en.pdf>. Access 15.12.2014

<sup>2</sup><http://www.cancerni.net/node/7336>. Accessed 15.12.14

<sup>3</sup>Thompson, M.J., Mills, M., Henderson, L., Lynas, C. (2013) *Developing new follow-up pathways for people with breast cancer: A review of the evidence*. <http://www.cancerni.net/publications/transformingcancerfollowupprogrammetheevidence> (Accessed 16<sup>th</sup> January 2015)

<sup>4</sup>Santin O.; Mills, ME.; Treanor, C.; Donnelly, M. (2012) *A comparative analysis of the health and wellbeing of cancer survivors to the general population*. Supportive Care in Cancer. 20(10): 2545-52

<sup>5</sup>Truesdale-Kennedy, M. Taggart, L. and Lupari, M. (2010) *Women's perceptions of the suitability and accessibility of breast cancer follow-up services*. Northern HSC Trust

<sup>6</sup>Lee, D. (2011) *Improving Cancer follow-up: An exploration of patients' views of routine follow-up after treatment for breast cancer and their openness to alternative methods of aftercare*

patient at the centre of the model; provides the right care in the right place at the right time; promotes integrated care; ensures sustainability of service provision, and maximises the use of technology.<sup>7</sup>

It is against this backdrop, the Transforming Cancer Follow-Up Programme (TCFU) in NI was developed. The programme commenced in January 2012 across the five Trusts in NI. The TCFU programme is a partnership between Macmillan Cancer Support (Macmillan), the Health and Social Care Board (HSCB) and the Public Health Agency (PHA), facilitated by NICaN. It is aligned with the National Cancer Survivorship Initiative and NHS Improvement Survivorship Pathways. Figure 1.1 charts the timeline for the TCFU programme in NI.

**Figure 1.1: Timeline for TCFU programme**



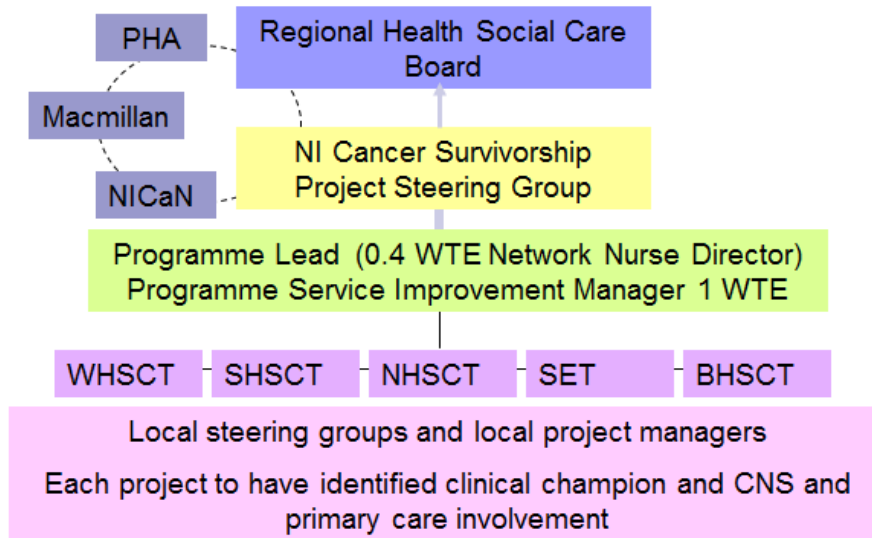
A range of methodological approaches were used to provide a framework for the programme, these included:

- service improvement;
- practice development;
- co-production principles;
- lean processes;
- project management, and
- realistic evaluation of the programme.

In terms of the programme structure, a regional steering group comprising key stakeholders has overseen the programme through quarterly meetings. The director of commissioning (HSCB) chaired the steering group. A small project team, funded by Macmillan was set up. This comprised a programme lead (0.4 WTE network nurse director) until March 2013, and 1 WTE survivorship programme manager, from September 2011, who became programme lead from March 2013. The project team works closely with each Trust to develop collaborative working arrangements and provide support to ensure the success of the overall programme. Trusts established local steering groups with executive leadership, identified trust lead(s), clinical leadership and primary care /Local Commissioning Group involvement. The extended project team comprises a project manager for each of the five Trusts and Trust cancer leads. Figure 1.2 below outlines the TCFU programme structure.

<sup>7</sup> <http://www.dhsspsni.gov.uk/index/tyc/tyc-timeline.htm> Accessed on 21<sup>st</sup> January 2015

**Figure 1.2: TCFU programme structure**

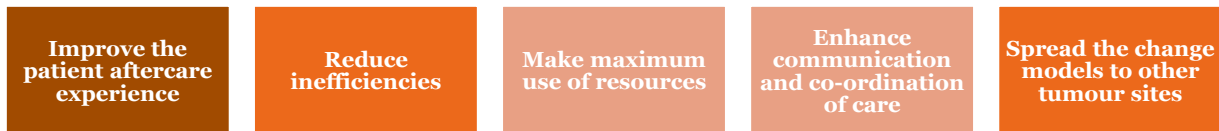


Source: NICaN

***The TCFU approach***

The TCFU project structure and outline was initially a two-year service improvement programme aimed at introducing and testing new models of cancer follow-up across NI, to begin to transform how such services are delivered. The aims of the programme are summarised in Figure 1.3.

**Figure 1.3: Aims of the TCFU programme**



The programme has both patient and service related objectives.<sup>8</sup>

The patient related objectives include:

- A holistic assessment, a Treatment Summary Record (TSR) and an agreed individualised pathway of care.
- Information tailored to patients’ needs, provided in an appropriate format, which signposts to services in support of self-management.
- A clear management plan and point of access back into the system if required.
- Guidance on lifestyle changes to maximise health and well-being, and which supports people getting their lives back on track.
- Information on the long-term effects of living with and beyond cancer.
- Better care coordination and an improved patient experience.

The service related objectives include:

- A reduction in the number of routine hospital follow-up appointments.

<sup>8</sup> NICaN TCFU Project Initiation Document January 2011



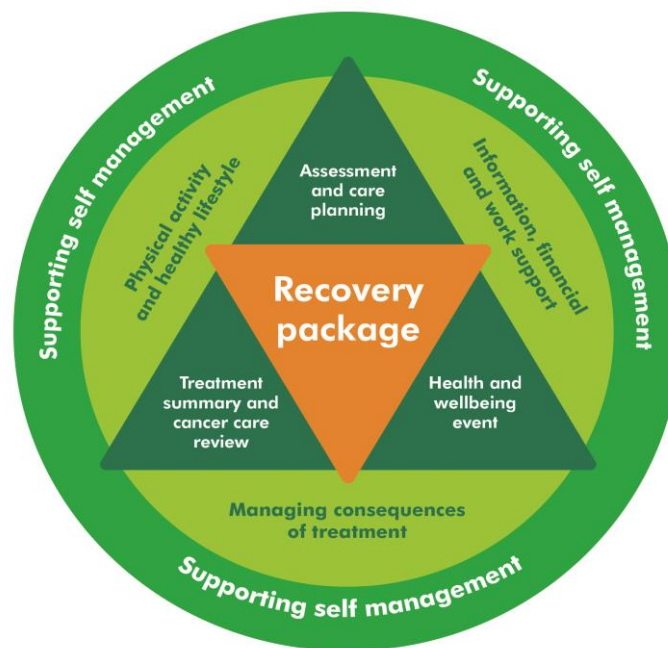
- A reduction in the duplication of follow-up between surgery and oncology.
- Better use made of skill mix initiatives in relation to cancer follow-up to create a more efficient and effective service.
- The development of regionally agreed risk stratification protocols.
- Holistic assessment for all patients and direction into the most appropriate aftercare pathway.
- Care coordination mechanisms and rapid access to services as required.

Collectively, the anticipated benefits from the programme are:

- improved patient satisfaction;
- effective resource utilisation, and
- streamlined services.

The TCFU programme is based on a risk stratified model of care, involving self-care with support and open access, and complex case management delivered by a multi-disciplinary team, with a strategic intention that the risk stratified approach becomes the normal practice. At the heart of the TCFU approach is the Recovery Package. The diagram below explains how the Recovery Package fits into an overall support of self-management for people living with and beyond cancer.

**Figure 1.4: The Recovery Package**



Copyright © Macmillan Cancer Support 2013  
Permission granted for use as seen, this notice must remain intact in all cases. All rights reserved.

The Recovery Package is a series of key interventions which, when delivered together, can greatly improve outcomes for people living with and beyond cancer. The interventions are: Holistic Needs Assessment (HNA); TSR; Cancer Care Review, and Health and Wellbeing Clinics. These elements are part of an overall support of self-management which includes physical activity as part of a healthy lifestyle, managing consequences of treatment, and information, financial and work support.<sup>9</sup>

---

<sup>9</sup><http://www.macmillan.org.uk/Aboutus/Healthandsocialcareprofessionals/Macmillansprogrammesandservices/RecoveryPackage/RecoveryPackage.aspx> Accessed on 31st January 2015

In addition to providing patients with a HNA, a TSR, and Health and Wellbeing events, the TCFU programme in NI offers an online tool for patients and their families. The NICaN Survivorship website ([www.survivorship.cancerni.net](http://www.survivorship.cancerni.net)) was designed for easy access by cancer survivors to find the services that will meet their needs, including a calendar of events, e.g. the health and wellbeing events organised by Trusts and self-management programmes and events available through a range of providers.

### ***The TCFU programmes***

Initially, the TCFU programme took forward two regional projects; one focused on breast cancer and one focused on prostate cancer, with the learning from these cancer sites to be applied to other cancer sites in the future. The two regional programmes within TCFU, namely, patients with breast cancer and patients with prostate cancer, are the focus of this evaluation.

Within the breast cancer project, the Self-Directed Aftercare (SDA) pathway was developed to support patients to get back to living their lives following treatment for breast cancer. The products for SDA include: a robust review mammography system, in line with NICE recommendations for surveillance; elimination of routine review appointments to bespoke appointments, with clinicians at key points on the patients journey; a rapid access facility for patients on the SDA pathway; education and information for patients; a HNA and care plan; a TSR; GP letters to inform them of the changing system, and health and well-being events.<sup>10</sup>

The prostate cancer project has been slower to develop, in comparison to the breast cancer project. This is partly to do with prostate cancer being more complex in the aftercare stages. A total of six pathways have been developed to take into consideration these complexities. There are currently four urology pathways consisting of raised prostate specific antigen (PSA); active surveillance; watchful waiting, and following radical prostatectomy. There are two oncology pathways: following radical radiotherapy, and following brachytherapy. At the stage of this evaluation only some of these pathways have been implemented across the five Trusts. The components of each of these pathways are: nurse-led follow-up; bespoke appointments with clinicians; telephone triage system, and the PSA IT tracker.<sup>11</sup>

The TCFU programme has been an evolving process, and Figure 1.5 sets out some of the key milestones in the breast<sup>12</sup> and prostate programmes, and the survivorship services.

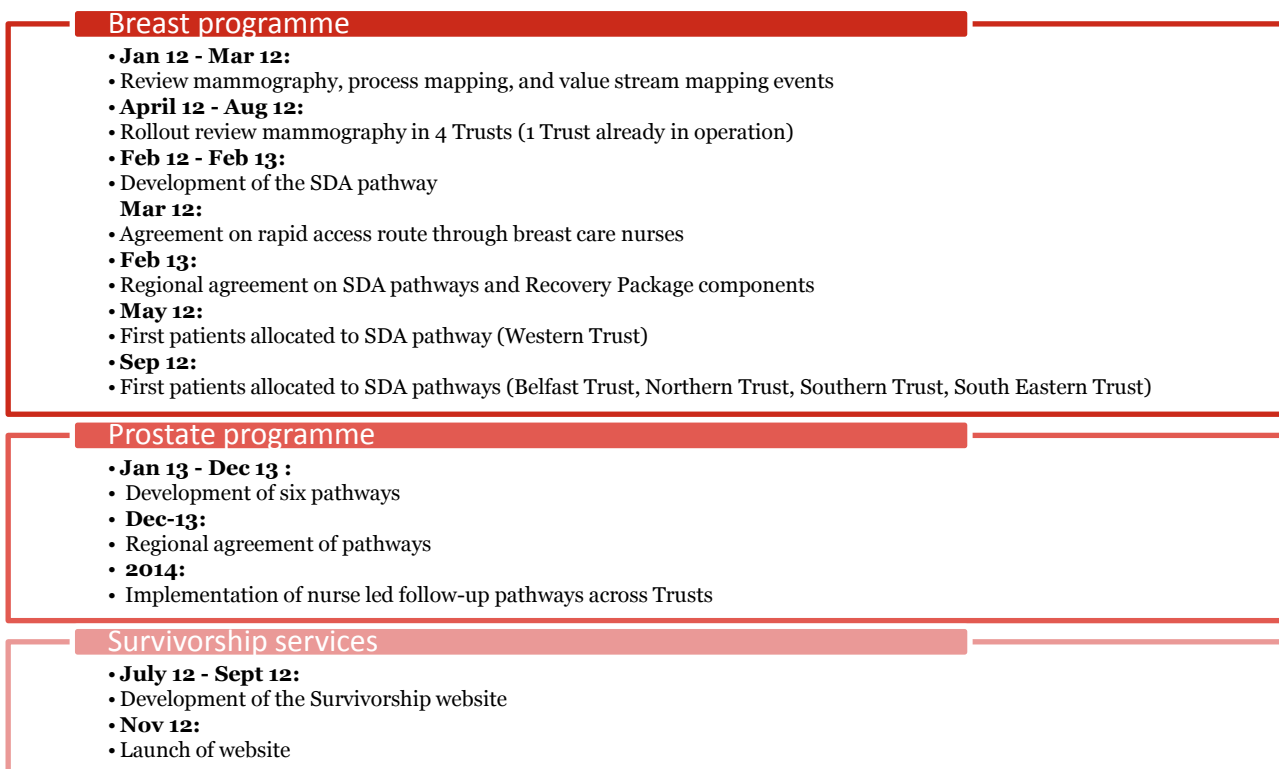
---

<sup>10</sup><http://www.cancerni.net/files/file/Transforming%20Cancer%20Follow%20Up/FINAL%20Breast%20Cancer%20SDA%20Protocol%20V9%20Sept13.pdf> Accessed on 21<sup>st</sup> January 2015

<sup>11</sup> Slides from the “*Sustaining the success of Transforming Cancer Follow UP Workshop*,” November 2014.

<sup>12</sup> Note that patients were allocated on to the SDA pathway as it was being refined, hence the final agreement occurring after the patient allocation to the pathway

**Figure 1.5: Key milestones breast and prostate programmes & survivorship service**

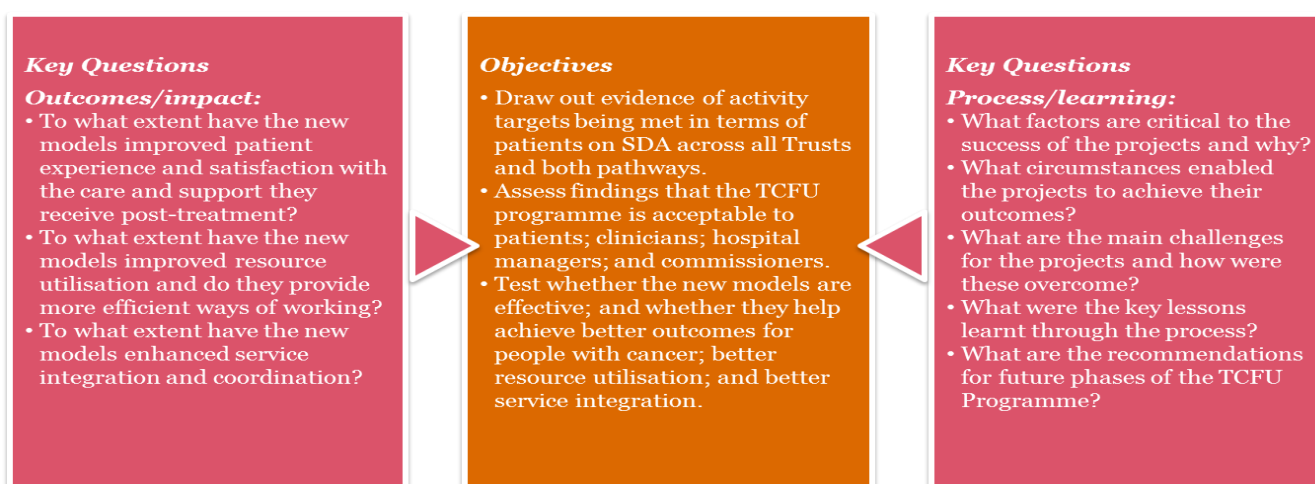


## ***Background to the evaluation***

### ***Aims and Objectives***

PwC was appointed by Macmillan in September 2012 to conduct an evaluation of the TCFU programme in NI. A number of key questions underpin the evaluation, as outlined in Figure 1.6.

**Figure 1.6: Aims and objectives of the evaluation**



## Methodology

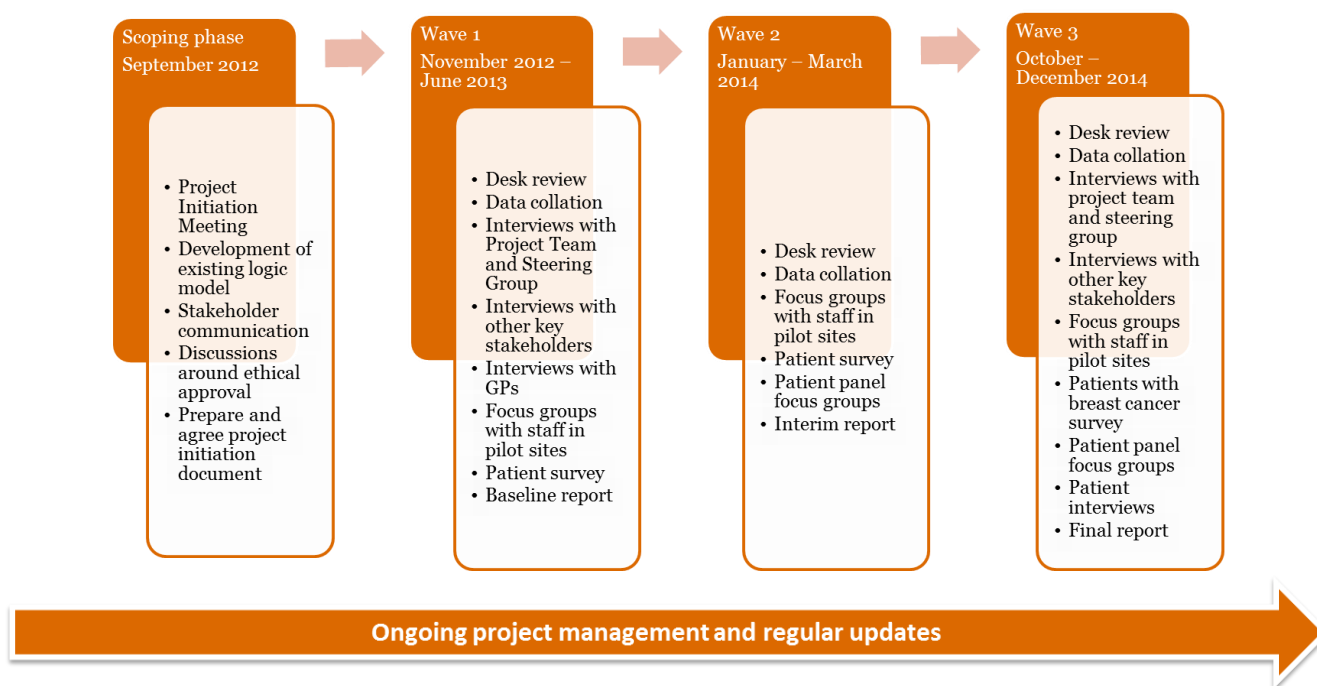
### Approach

An evaluation advisory group (EAG) was established to support the evaluation and the PwC evaluators worked closely with the group throughout the evaluation. In line with guidance from the National Research Ethics Services (NRES) on ethical approval, this evaluation fits well with NRES's definition of "service evaluation."<sup>13</sup> In addition to collaborating with the EAG, the evaluators also discussed and agreed the methodological approach with the five Trusts, liaising with those responsible for research and evaluation within each Trust. All Trusts agreed that ethical approval was not required.

The evaluation was commissioned as a formative evaluation over a two year period. The EAG provided ongoing advice and clinical guidance to the evaluators on the approach, the evaluation tools, and reporting. There were three waves in the evaluation, with a report provided on the completion of each wave. Findings from waves 1 and 2 were used to inform the development of the programme. This report is the third and final report and consists of data from wave 1, wave 2 and wave 3.

Figure 1.7 provides an overview of the methodology used in each wave of the evaluation; appendix 1 provides full details of the methodology. Evaluation tools for each wave are contained in appendix 2.

**Figure 1.7: Methodological approach of the evaluation**



The desk based review consisted of data received from the five Trusts and the Macmillan and NICaN project team. This data was collated and provided to the evaluators and included:

- numbers of patients on the SDA pathway;

<sup>13</sup> According to NRES, although some research projects include evaluation, where a project is considered to be solely audit or service/therapy evaluation, it will not be managed as research within the NHS or social care. Such projects do not require ethical review by a NHS or Social Care Research Ethics Committee or management permission through the NHS R&D office. Under these circumstances, there is no need to submit applications to the NHS Research Ethics Committee (REC) or NHS/HSC R&D office. *National Research Authority (2009) Defining Research, NRES guidance to help you decide if your project requires review by a Research Ethics Committee.* Available online: <http://www.nres.nhs.uk/applications/is-your-project-research/> [Accessed on 13<sup>th</sup> January 2015]

- duplication between breast surgical and oncology appointments;
- single speciality waiting lists;
- waiting lists for breast oncology;
- patients waiting past their indicated appointment for oncology breast review;
- number of hits on NICA survivorship website, and
- number of attendees at health and wellbeing events.

In addition, the evaluators were provided with an update on each Trust's progress in implementing the six prostate pathways, together with a report from the Western Trust on the optimisation of the PSA IT tracking system in the Western Trust (*see appendix 5*).

Both quantitative and qualitative methods were used throughout the evaluation. An overview of the methodological approach used in each wave is provided in table 1.1 and table 1.2, as well as in appendix 1.

**Table 1.1: Quantitative approaches**

<i>Surveys administered and response rates</i>			
	<i>Wave 1 baseline survey with patients diagnosed with breast cancer</i>	<i>Wave 2 baseline survey with patients diagnosed with prostate cancer</i>	<i>Wave 3 survey with patients diagnosed with breast cancer</i>
<i>Total surveys sent</i>	234	247	250
<i>Total responses received</i>	115	147	146
<i>Percentage response rate</i>	49%	60%	58%

Source: Data collated on survey responses received, throughout the evaluation (Wave 1 – wave 3)

**Table 1.2: Qualitative approaches**

<i>Interviews and Focus Groups (number of participants)</i>				
	<i>Wave 1</i>	<i>Wave 2</i>	<i>Wave 3</i>	<b><i>Totals</i></b>
<i>Wider stakeholder<sup>14</sup> interviews</i>	18	27	12	<b>57</b>
<i>Trust staff<sup>15</sup> focus groups<sup>16</sup></i>	62	20	45	<b>127</b>
<i>Wider stakeholder focus groups</i>	11	6	5	<b>22</b>
<i>Focus groups with patients diagnosed with breast cancer</i>	8	0	12	<b>20</b>
<i>Focus groups with patients diagnosed with prostate cancer<sup>17</sup></i>	0	0	6	<b>6</b>

Source: Data collated on evaluation participation (Wave 1 – wave 3)

## **Data analysis**

PwC collected a variety of qualitative data in each wave, using the methodologies outlined above. The data was collated into summary templates. Thematic analyses documents were created for each of the evaluation participants (patients with breast cancer; patients with prostate cancer; Trust staff; GPs; the steering group and project team, and voluntary representatives).

<sup>14</sup> Wider stakeholder includes GPs, voluntary sector representatives, and members of the project team

<sup>15</sup> Trust staff includes clinicians, clinical nurse specialists, project managers, admin staff

<sup>16</sup> Focus groups with Trusts staff, patients and wider stakeholders were attended by up to 10 participants, with an average of 7 participants in each

<sup>17</sup> An interview was carried out with a patient who could not attend a focus group, at their request

Data analysis software was used to identify trends from the patient survey responses and a variety of charts were created demonstrating the findings. Comparative analysis was carried out between the survey responses collated in wave 3 and those in waves 1 and 2. The surveys conducted in waves 1 and 2 were baseline surveys with patients on the traditional follow-up models for breast and prostate cancer. Thematic analysis was applied to the qualitative questions contained within the surveys.

### ***Methodological considerations***

In undertaking this evaluation, we have endeavoured to employ a robust and comprehensive evaluation approach. As with any evaluation, however, we have made a number of assumptions and encountered some limitations, which are outlined below.

#### **Assumptions**

Data provided by Trusts, NICaN and others to inform this evaluation is assumed to be correct. We have not validated or audited data provided to us.

The evaluators have used their skills in qualitative data gathering, probing and critical analysis, to elicit open and honest views from wider stakeholders<sup>18</sup>. From this, we have assumed that views from these evaluation participants are representative of others in their organisation, profession and/or sector.

#### **Limitations**

Due to the slower development of the prostate stream of the programme, the evaluators have been limited in terms of availability of data for patients with prostate cancer. Pathways were agreed during the course of the evaluation. However, Trusts are at varying degrees of implementation, which is demonstrated by the fact that not all six pathways have been implemented in every Trust across NI. This resulted in less focus in the evaluation on prostate cancer than would have been anticipated at the commencement of the evaluation. For example, we only have baseline survey information from patients with prostate cancer, and compared to the breast programme, fewer participants within the prostate programme participated in the fieldwork throughout each wave of the evaluation. This is primarily because the prostate pathways have not been fully rolled out.

In addition to these methodological constraints, the TCFU programme in NI is a regional strategic approach to transforming cancer services, whereas, elsewhere in the UK, other initiatives have been confined to single Trusts or to specific aspects of new models of care. Therefore, no comparable literature is currently available on the success, or otherwise, of such programmes which could be used as a suitable benchmark.

Finally, it must be noted that due to data protection laws, the samples for the survey with patients diagnosed with breast cancer were chosen by the project managers in each Trust. PwC had no responsibility for producing the random sample of 50 SDA patients from each Trust (*please see information on the distribution process in appendix 2*).

The remainder of this report is structured around the aims of the programme, as follows:

2. Improving cancer patients' aftercare
3. Improving resource utilisation
4. Enhancing the coordination and integration of care
5. Learning from the programme
6. Areas for consideration

---

<sup>18</sup> Wider stakeholders refers to HSC Trust staff, TCFU project team, GPs, voluntary and community representatives

## ***2. Improving cancer patients' aftercare experience***

*"I know if there are any issues or problems, I can talk to a number of breast care nurses. I saw two nurses who were so friendly. I had reservations but now I'm happy."*

(Patient with breast cancer)



## Introduction

An integral part of the TCFU breast programme is the SDA. This is offered to patients with breast cancer who are treated with curative intent. The key consideration for patient inclusion is their ability to self-manage. The products for SDA include: a robust review mammography system in line with NICE recommendations for surveillance; elimination of routine review appointments to bespoke appointments with clinicians at key points on the patients journey; rapid access facility for patients on the SDA pathway; education and information for patients; a HNA and care plan; a TSR; GP letters to inform them of the changing system, and health and well-being events. Key to the implementation of the SDA is the Clinical Nurse Specialist (CNS), who provides holistic follow-up for cancer patients, including signposting to the community and voluntary sector.

Research has shown that when patients with prostate cancer have finished treatment they often have difficulties returning to normal life and may experience side effects which require significant life adjustments.<sup>19</sup> The aim of the TCFU programme is to improve the aftercare experience for these patients. In order to achieve this, six regional clinical pathways have been developed and a fully integrated PSA IT tracking system has been secured within the Regional Information System for Oncology and Haematology (RISOH). Work has also commenced on the recovery package for prostate cancer. Similar to the breast programme, the CNS plays a key role in providing nurse led follow-up.

This section of the report sets out the findings of the evaluation in relation to the aftercare experience of patients with breast and prostate cancer. It is structured around progress, impact, and challenges.

## Progress

A range of data has been collated in relation to the breast SDA pathway in terms of the numbers of patients on SDA, and other activity associated with the pathway. The findings from these data are reported in this section. These findings are supported with qualitative data obtained from the focus groups and interviews, and quantitative data from the survey carried out with patients diagnosed with breast cancer. Appendix 3 contains a range of charts which illustrate the survey findings some of which are reported in this section of the report.

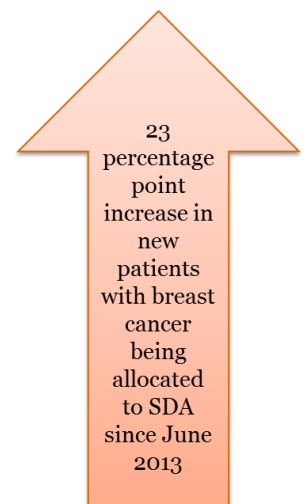
### Breast cancer programme

#### New and existing patients with breast cancer on SDA

The most recent data received from all Trusts (September 2012 – January 2015) show that 1971 patients across NI are now on the SDA pathway. This is comprised of 1331 new patients with breast cancer and 640 existing review patients. For year three of the SDA pathway, this represents 58% of **new** patients on the pathway. When broken down into each Trust, the new SDA patient numbers as of December 2014 are: Northern Trust (222); Southern Trust (182); South Eastern Trust (177); Belfast Trust (327), and Western Trust (423). By comparison, as of June 2013 (at the time of the wave 1 report) 35% of newly diagnosed patients with breast cancer across the five Trusts were allocated to the SDA pathway.

This suggests that confidence in the programme is building. Clinicians are now allocating both new and review patients to the SDA pathway.

An audit was carried out at different four week periods across all five Trusts to determine the reasons why patients were not suitable for the SDA pathway. Notably there are variations in the numbers of patients being allocated to the pathway month to month, and the audit indicated a number of reasons:



Source: Desk review data of SDA patient figures from all 5 HSC Trusts (January 2015)

<sup>19</sup> NICaN/ Macmillan (2010) *Post Cancer Treatment Follow-Up - Managing Demand and Expectations*  
<http://www.cancerni.net/publications/transformingcancerfollowupearlyworkshops> Accessed 26th June 2013



further surgery or results were awaited; advanced disease; family history, or because they are unable to cope with their diagnosis.

### Other activity associated with the SDA pathway

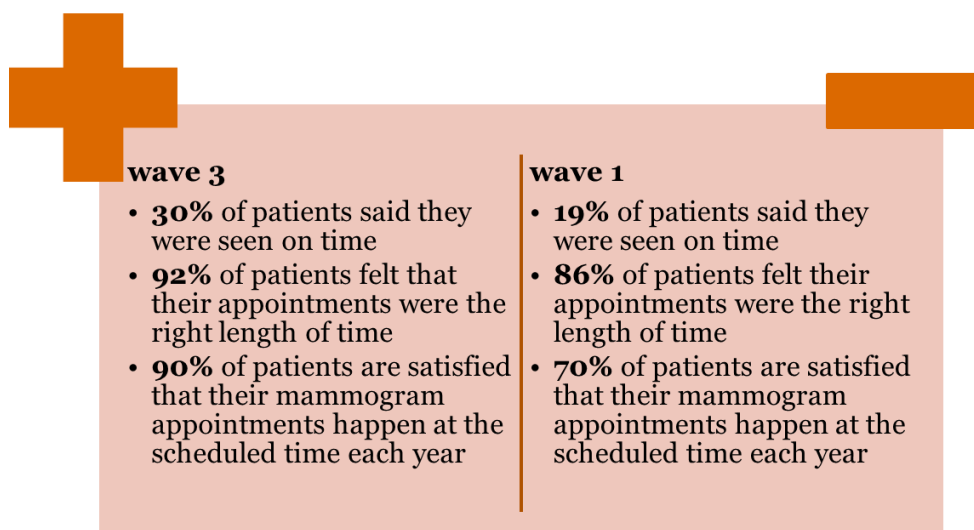
Data has been collated on activity associated with the SDA pathway. As of January 2015 across all five Trusts there were:

- 230 rapid access calls received, representing 12% usage by SDA patients, of which:
  - 38 required a breast care nurse appointment, and
  - 154 required a consultant appointment, representing 8% usage.

The data from the survey support these positive findings in that over twice as many respondents to the survey in wave 3 indicated that they had been referred to their breast care nurse (53% in wave 3, compared to 25% in wave 1); 32% of patients in wave 3 said they were offered a care plan, compared to 12% in wave 1 (*please see charts 3 and 23 in appendix 3*).

The data from the surveys carried out with patients diagnosed with breast cancer show improvements between wave 1 and wave 3, in terms of patient satisfaction with the scheduling and timing of their appointments. These findings are illustrated in Figure 2.1:

**Figure 2.1: Patient satisfaction with scheduling and timing of appointments**



Source: Data collated from the survey with patients diagnosed with breast cancer, conducted in wave 3 (n=146), and the baseline survey conducted with patients diagnosed with breast cancer in wave 1 (n= 115)

In addition Health and Social Care (HSC) Trust staff reported feedback from patients indicating that they were happy with fewer review appointments, as this had reduced their anxiety. This view was supported by the small number of GPs<sup>20</sup> who were interviewed in wave 3, who highlighted that often their patients would worry about an annual review appointment for months in advance. All wider stakeholders agreed that the mammography system has resulted in improved waiting times and in fewer unnecessary appointments, thereby saving the patient having to make multiple trips to the hospital.

<sup>20</sup> 2 GPs were interviewed in wave 3; both had participated in the programme

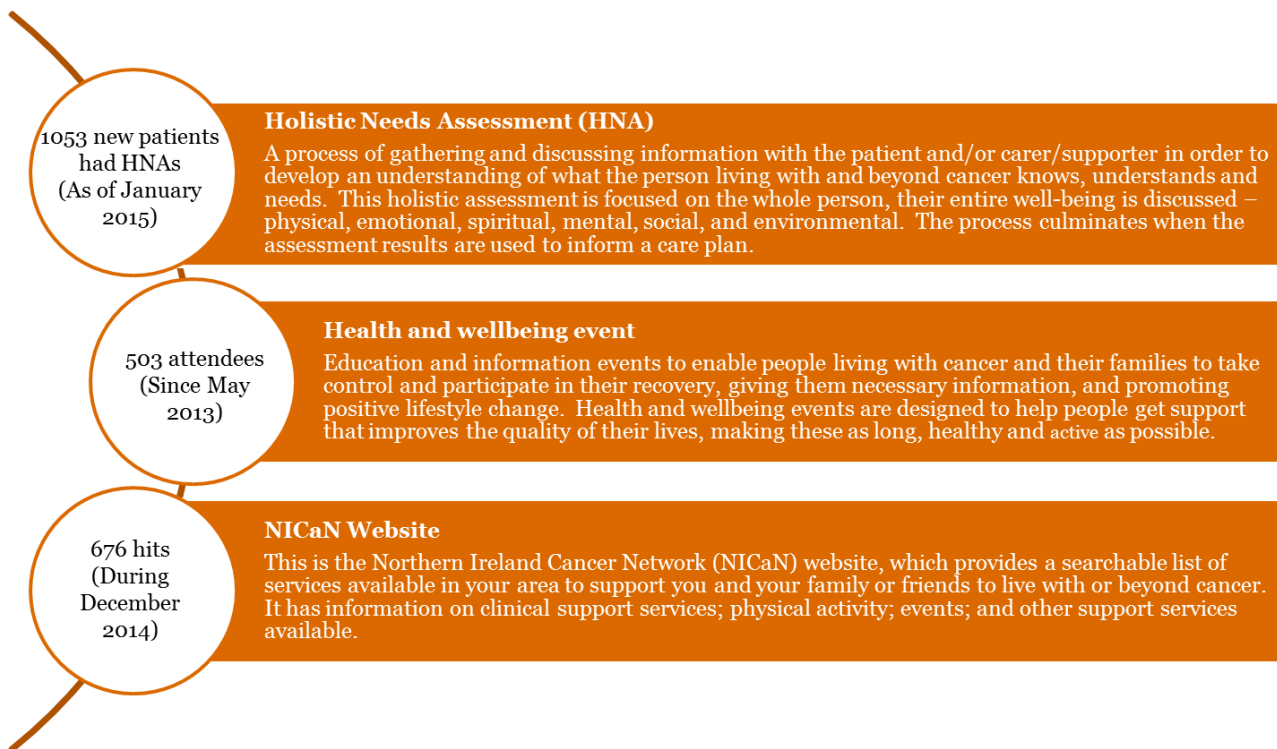
Wider stakeholders perceived that aftercare had changed for the better. GP participants highlighted that whilst there were reservations initially, the programme has helped patients to think differently about their care and they no longer feel tied to the hospital. The greater focus on survivorship was welcomed by wider stakeholders.

### HNAs, health and wellbeing events and NICaN survivorship website usage

Data was collated on the number of HNAs undertaken, the number of Health and Wellbeing events held (along with the number and nature of attendees) and the website usage (i.e. hits on website). The most recent cumulative data shows that, as at January 2015, 1053 new patients have had a HNA rising from 476 as of March 2014; this represents 53% of all patients now on the SDA pathway, compared to 47% of all SDA patients in March 2014.

The number of hits on the website has increased from 191 hits per month in January 2013 to 676 hits in December 2014; these represent a range of individuals, including patients with breast cancer. The most recent cumulative data, along with a comparison of the situation at the time of the wave 1 evaluation, shows there is a continuous uptake of the health and wellbeing events. In total since May 2013, there have been 503 attendees at the health and wellbeing events.<sup>21</sup>

**Figure 2.2: TCFU programme features**



Source: Desk review data on HNAs, health and wellbeing events, and website usage, collated in wave 3 and definitions taken from the National Cancer Survivorship Initiative website <sup>22</sup>

## **Prostate programme**

The prostate programme, although slower to be implemented than the breast programme, has made some considerable progress, particularly in terms of implementing the various pathways. The Western Trust has made the most progress due to having a number of developments underway before the introduction of the

<sup>21</sup> This figure is from the desk review of data supplied by all five Trusts on patient attendance rates at health and wellbeing events

<sup>22</sup> Definitions taken from the National Cancer Survivorship Initiative website- [www.ncsi.org.uk](http://www.ncsi.org.uk) (Accessed on 7<sup>th</sup> January 2015)

TCFU programme; in particular the PSA IT tracking system. The Trust has been able to enhance its progress in implementation, with TCFU resources, and the pathways are now going through the local processes for implementation.

Other Trusts have made progress in implementing some of the pathways under the TCFU programme, with movement of patients onto these pathways, although numbers do remain small. The Northern Trust is currently undertaking a pilot of nurse led telephone follow-up for patients, and they have had 130 patients on this pathway, with all patients having received a HNA. The Belfast Trust has implemented five of the six pathways with two CNSs providing nurse led follow-up. A two month audit carried out of the nurse led clinics, within the Belfast Trust, was extrapolated for 2014, and this estimated a release of 856 consultant appointments for 2014. The South Eastern Trust has had patients move onto three of the pathways under TCFU. The Southern Trust commenced nurse-led pathways for watchful wait and active surveillance in October 2014, and CNS job plans have been reconfigured to support these.

There has also been a good uptake of the health and wellbeing events for the prostate programme in some of the Trusts. For example, in the Northern Trust they have had over 70 attendees at an event and the Western Trust held an event on the 20<sup>th</sup> October 2014 which was attended by over 50 people.

## Impact

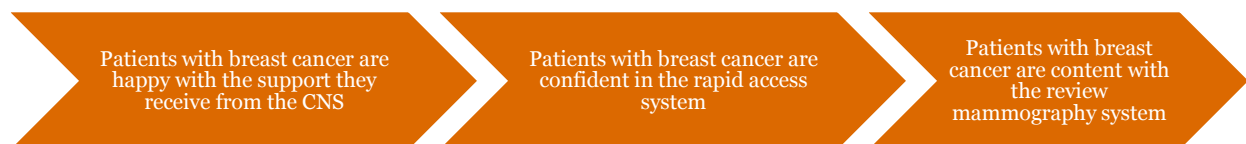
This section reports on the impact of the TCFU programme on the aftercare experience of patients diagnosed with breast and prostate cancer. The data is derived from the survey with patients who had been diagnosed with breast cancer, and from the focus groups and interviews with patients diagnosed with breast and prostate cancer, as well as the focus groups and interviews with wider stakeholders. Comparisons are provided with the data collected in the previous two waves, which consisted of baseline data collected from patients who were on traditional models of follow-up.<sup>23</sup>

### ***The views of patients with breast cancer on the impact of TCFU***

Most patients with breast cancer were not aware of the services provided by the programme by name (e.g. HNA), and they were generally unaware about being on the SDA pathway. A patient diagnosed with breast cancer, who attended one of the two focus groups, stated: “I am not sure if I am on SDA or not, but I got all the information; I know the name of my nurse.” Another patient believed that the SDA pathway was the only pathway option within breast cancer. Responses from the data collected through the survey with patients diagnosed with breast cancer were similar. For example, all patients who were surveyed were on the SDA pathway but only 88 of 143 respondents indicated “Yes” when asked if they were on the SDA pathway (*please see chart 9 in appendix 3*).

Notwithstanding the above, patients identified positive impacts resulting from being on the SDA pathway. In particular, the combined safeguards of the rapid access system and review mammography system are helping to alleviate the concerns patients might have about getting lost in the system during their aftercare. These findings are illustrated in Figure 2.3.

**Figure 2.3: Aspects of care which patients with breast cancer were happy with**



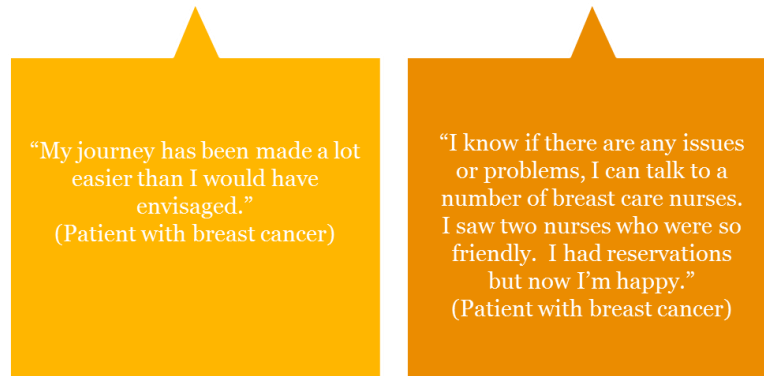
Source: Data collated through focus groups with patients diagnosed with breast cancer

In addition, the majority of survey respondents were satisfied with the amount of information they had received on accessing support services. Moreover, over 80% of patients with breast cancer, who were surveyed in wave 3

<sup>23</sup> The baseline patient survey in wave 1 was conducted with patients with breast cancer, who were on the traditional model of follow-up. The baseline patient survey in wave 2 was conducted with patients diagnosed with prostate cancer, who were on the traditional model of follow-up

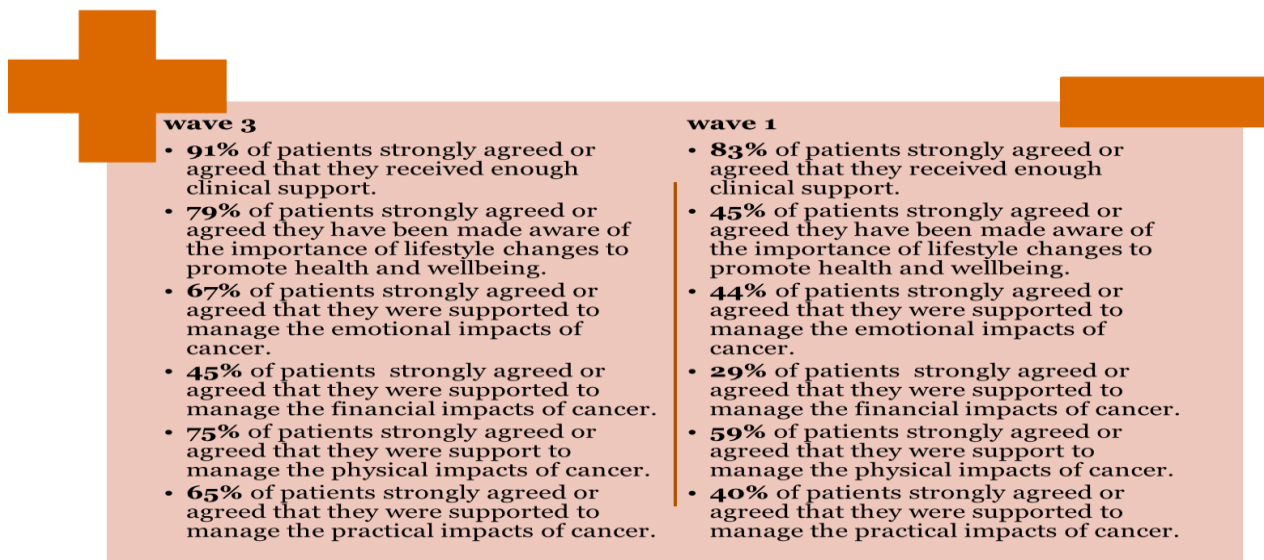
indicated that they had received enough information on the support services available after treatment; this is compared to 51% of patients with breast cancer on the traditional model of follow-up, who were surveyed in wave 1 (see charts 4 and 16 in appendix 3).

**Figure 2.4: Views of patients diagnosed with breast cancer**



Survey respondents were also asked to provide their views on the range of cancer care and support services provided to them. Compared to wave 1, more patients in wave 3 were more likely to strongly agree or agree that they were supported to manage the emotional, physical and practical impacts of cancer. For example, over 60% of survey respondents in wave 3 strongly agreed/agreed that they had been supported to manage the practical (65%), emotional (67%) and physical (75%) impacts of their cancer.<sup>24</sup> However, notwithstanding the improvements in patient satisfaction, it is notable that less than half of the survey respondents in wave 3 strongly agreed/ agreed that they had been supported to manage the financial impacts of cancer (please see chart 23 in appendix 3). This would suggest that further efforts could be made to provide this type of support.

**Figure 2.5: Views of patients with breast cancer on the support received throughout their aftercare**



Source: Data collated from the survey carried out in wave 3 and the baseline survey conducted in wave 1 (respondents are all patients diagnosed with breast cancer)

<sup>24</sup> Please note, a few patients with breast cancer who participated in one of the focus groups did express a desire for more support to manage the practical impacts of cancer; in particular help with finding mastectomy underwear

The majority of patients with breast cancer who participated in the focus groups indicated that they were comfortable with managing their own care, although a small number of patients were not. For example, there was a feeling from some patients that their aftercare experience had led to them feeling “abandoned”; in particular those patients who only had surgery felt anxious about being left alone for the first few months. It was suggested by a number of patients that it would be beneficial to have the nurse check in with the patient. Some patients felt uncomfortable contacting their nurse about every issue, with one saying “*How do I know if something is a worry?*”

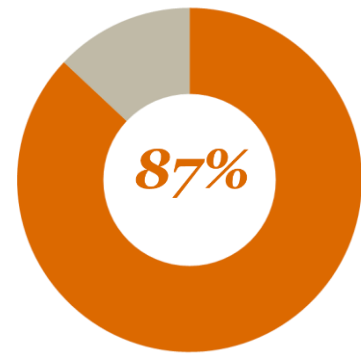
In addition, not all patients had been made aware of, or had participated in health and wellbeing events. For example, a few of the participants had been enrolled in fitness workshops, whereas other patients were not aware that these were accessible to them.

Most patient focus group participants were not aware of the NICaN survivorship website. When these patients were probed about the websites they did use, it became clear that there was reluctance by some patients to use the internet as they were concerned about reading something which may alarm them. This suggests that there may be a need for CNSs and clinicians to promote the survivorship website more effectively by highlighting that the website has been set up to help patients cope with their diagnosis, and to provide helpful support and information from trusted sources. One of the patients commented that she had probably been given information on the website but that she had not yet gone through the whole information pack, as there was a lot to read.

Overall, patients with breast cancer who were on the SDA pathway have had a positive aftercare experience. The majority (87%)<sup>25</sup> of patients with breast cancer, who were surveyed in wave 3, were satisfied with their overall aftercare (*please see chart 24 in appendix 3*). Generally, focus group participants concurred with this view. One participant indicated that the SDA pathway had made her recovery process a lot easier than anticipated.

### Key features of the programme for patients with breast cancer

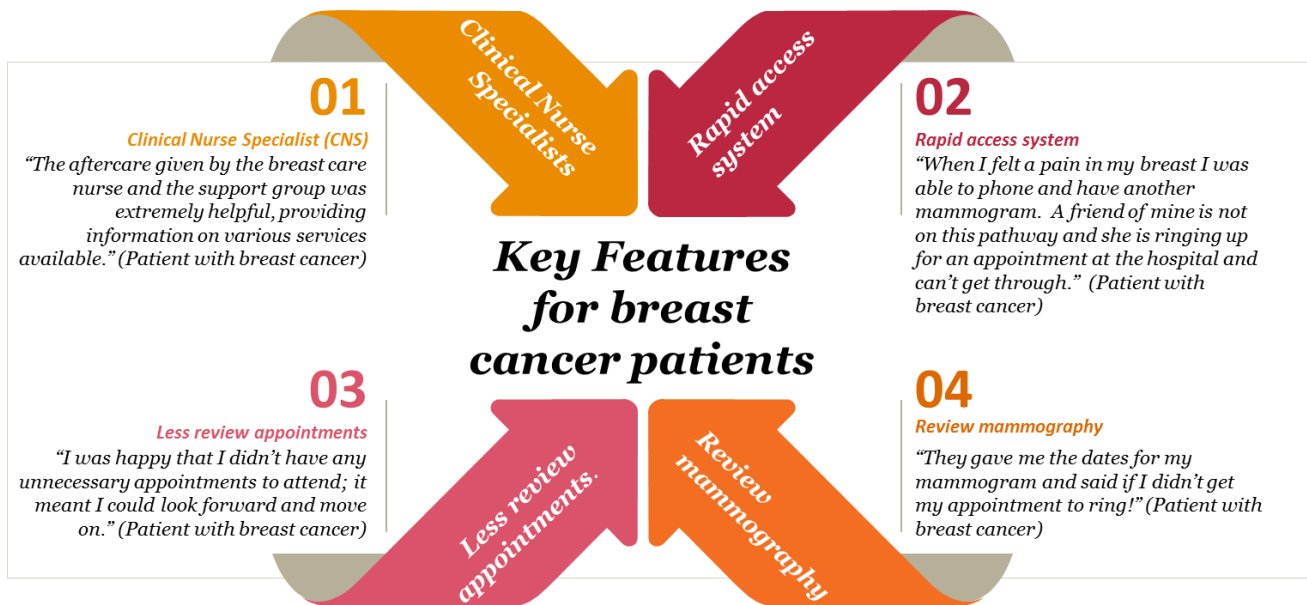
Patients with breast cancer identified four key features of the programme - their CNS, the rapid access system, fewer review appointments and the review mammography system. Overall, patients felt reassured by the accessibility of the service provided and by the approachability of their CNS. In addition, patients were relieved to have their mammogram appointments and it was noted that this had significantly eased anxiety. These views are illustrated in Figure 2.6. Whilst most patients expressed the view that it was empowering to have fewer review appointments with a consultant, there were some reported differences in opinions between patients who had surgery without treatment, and those patients who had surgery followed by treatment, with a small number of surgical patients expressing a sense of “abandonment”.



*87% of patients diagnosed with breast cancer who responded to the survey were satisfied with their aftercare.*

<sup>25</sup> Please note that around 6% of patients with breast cancer respondents answered neither/ nor when asked if they were satisfied with their breast cancer follow-up care. A total of 6% disagreed/ strongly disagreed that they were satisfied with their breast cancer follow-up care and 1% did not answer this question

**Figure 2.6: Key features of the programme for patients with breast cancer**



Source: Data collated through focus groups and a patient survey in wave 3

### **Views of patients with prostate cancer on the impact of TCFU to date**

Due to the programme being slower to embed, there is less evidence from patients diagnosed with prostate cancer on the impact of the programme. Notwithstanding, those patients who participated in wave 3<sup>26</sup> of the evaluation did report benefits as a result of the new follow-up arrangements.

The findings from wave 2 relate to 147 patients with prostate cancer, who were on the traditional model of follow-up, and who responded to the wave 2 baseline survey. Compared to responses in relation to the physical impacts of cancer, respondents to the wave 2 baseline survey, (who were on the traditional model of follow-up) were less likely to strongly agree or agree that they were supported to manage the wider impacts of cancer across all categories. In particular, most respondents were more likely to answer "neither/ nor" when asked whether they have been supported to manage the emotional, financial and practical impacts of cancer.

The six patients diagnosed with prostate cancer, who participated in the evaluation in wave 3, (all of whom were on the new pathway) were happy with the support and information they had received on dealing with the wider impacts of cancer. In particular, some patients indicated that they had been helped by attending a support group organised by Macmillan. Some patients had found it helpful to receive information on the financial assistance that might be available to them. However, some of these patients felt they would have benefitted from additional support in dealing with the emotional impacts of cancer.

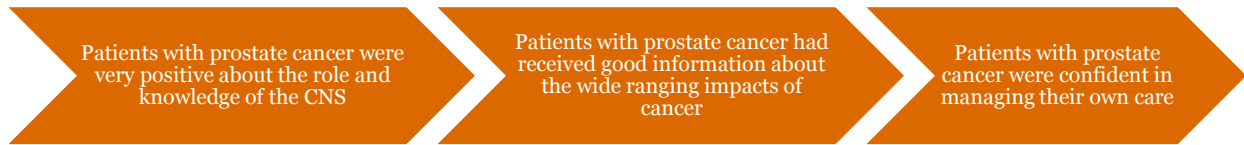
Although these patients felt they had received adequate information from their CNS on the different impacts of cancer, in general there appears to have been a lack of signposting to further information and support services; in fact most of the patients who participated in the wave 3 focus group stated that they had not been signposted to any community services. In addition, most of these patients were not aware of the NICaN survivorship website. Notwithstanding all of these comments, all of the patients who had been diagnosed with prostate cancer, and who were consulted in wave 3, said that they felt confident to manage their own care. All of these patients understood the different aspects of their aftercare, although they were not aware of the service offered to them by name. They were also very positive about the role of the CNS and had received sufficient information

<sup>26</sup> A total of six patients with prostate cancer participated in wave 3 of the evaluation (five patients participated in a focus groups and one patient was interviewed)



on the wide ranging impacts of cancer (see Figure 2.7), albeit as noted above, some would have liked more help with managing the emotional impacts of cancer.

**Figure 2.7: Positive aspects of care for patients with prostate cancer**



Source: Data from the focus groups and interview conducted in wave 3 with six patients diagnosed with prostate cancer

The six patients that participated in wave 3 of the evaluation highlighted that the length of time they spent with their CNS was sufficient and that they had less anxiety because they knew they had direct access to their nurse. The best aspects of their aftercare were being able to contact the CNS when they had a query, and the reassurance of being able to see their consultant if necessary.

Only a few of the patients with prostate cancer, who participated in the wave 3 focus groups, had attended health and wellbeing events. It was mentioned during the focus group that only patients who had been recently diagnosed with prostate cancer had been invited to attend the most recent health and wellbeing events, although all of the focus group participants, irrespective of when they were diagnosed, indicated that they would like to attend these events.

### Key features of the programme for patients with prostate cancer

Similar to patients with breast cancer, patients with prostate cancer, who participated in wave 3, highlighted that the role of their CNS was critical to their aftercare experience, particularly in providing the necessary support and information to deal with the impacts of cancer. The majority of patients were happy that they were able to contact a nurse through a triage system, and believed that this contributed to them having faster treatment or support. In addition, most of these patients identified that the support groups organised by Macmillan were very beneficial to them.

*"In between my consultant appointments I would give my nurse a call with any queries. I know I can phone her with any problems and be seen right away." (Patient with prostate cancer)*

*"My contact is with my nurse and I have the confidence that I can talk to her." (Patient with prostate cancer)*

*"The work my nurse does has been great; she is as good as any consultant." (Patient with prostate cancer)*

*"The support groups should continue as these are helpful to patients." (Patient with prostate cancer)*

### Wider Stakeholders' views on the impact of TCFU

Wider stakeholders spoke about how patients with breast and prostate cancer are now considered beyond their clinical need. Most wider stakeholders agreed that the recovery package has played a key role in improving the patient experience; in particular the HNA and the health and wellbeing events. However, whilst the health and wellbeing events were important in improving the patient aftercare experience, it was felt by some wider stakeholders that these could be improved upon with greater involvement of patients and the voluntary sector, and by issuing more personal invitations to patients.

Trust staff felt that it was important for the programme to continue to be flexible in order to make sure that patients' needs are paramount and that it should continue to be confined to patients who are deemed suitable for the pathway. In addition, one Trust representative felt that the programme could be made more bespoke, in order to appropriately address the needs of each individual Trust in terms of its patient population. In terms of the adaptability of the programme, the following positive features were noted by wider stakeholders:

- Different pathways for patients with prostate cancer which are tailored to different needs.
- Careful selection of SDA patients to ensure suitability for the programme.

- Individualised follow-up of patients, which enables holistic needs to be identified and addressed.
- The regional approach, which has resulted in greater consistency of care across Trusts, particularly in relation to patients with breast cancer.

Most of the wider stakeholders felt that patients were getting the right support and information in order to manage their own care. Trust staff felt that the focus on self-management meant that patients had more of a gradual exit from hospital treatment. GP participants felt that patients were now in the mind-set to take ownership of their condition, and that the programme encouraged this, although some Trust staff felt there was still a need to change the mind-set of some patients.

All wider stakeholders agreed that patients with breast and prostate cancer have had a positive experience with their CNS. Trust staff had received very positive feedback from patients about the direct contact with the CNS. It was thought that having one to one time with the nurse contributed to a better aftercare experience. Similarly, voluntary sector participants believed that the role of the CNS was pivotal to the aftercare experience.

**Figure 2.8: Quotations from wider stakeholders on the TCFU programme**



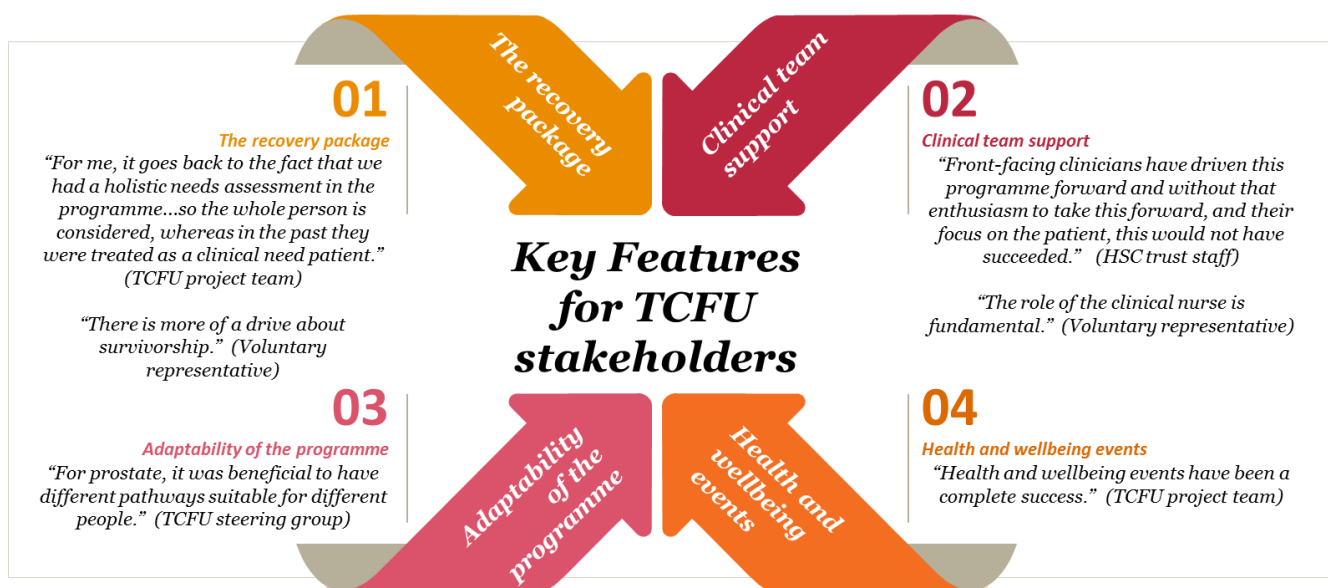
### Key features of the programme for wider stakeholders

Wider stakeholders identified the key features of the programme as being:

- the Recovery Package;
- clinical team support;
- the adaptability of the programme, and
- the health and wellbeing events.

These views are further illustrated in Figure 2.9.



**Figure 2.9: Key features of the programme for TCFU wider stakeholders**

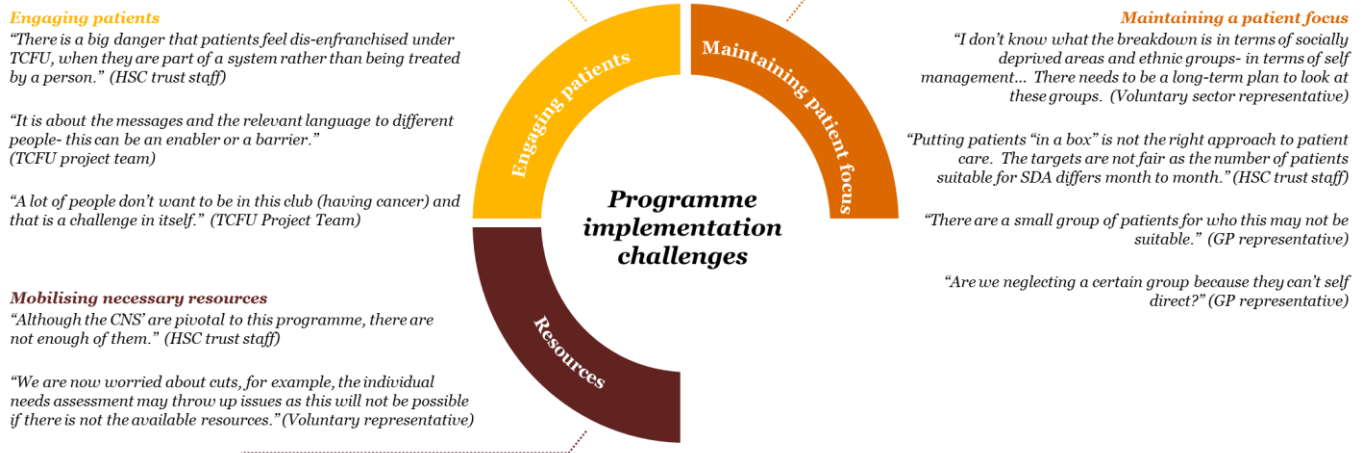
Source: Data collated through interviews, and focus groups in wave 3

## Challenges

Some key challenges emerged, in terms of sustaining a positive patient aftercare experience. These focus on engaging patients, maintaining a patient focus, and providing the necessary resources (see Figure 2.10).

- First, whilst there is good uptake of the programme, there is an ongoing challenge to change the mind-set of patients to be less focussed on the hospital/clinical setting. In order to overcome this challenge, the language used to promote and explain the programme needs to appeal to the patient.
- Second, the challenge of keeping the programme patient focused was identified by wider stakeholders. Some HSC Trust staff expressed concerns about the TCFU targets, stating that there are differences month to month in the number of patients with breast cancer who are suitable for the SDA pathway. There were also some concerns about patients who are not considered suitable for the TCFU programme. For example, one of the voluntary representatives highlighted the need to consider different groups, such as ethnic minorities and those from socially deprived areas.
- Third, there is a need for the ongoing support of clinicians, particularly within the prostate programme.
- Finally, the challenge of mobilising the necessary resources, particularly having sufficient CNSs to work across HSC Trusts, was highlighted as critical to the ongoing success of the programme, and to maintaining a positive patient experience.

**Figure 2.10: Programme implementation challenges affecting the patient aftercare experience**



Source: Data collated through interviews, focus groups and a patient survey in wave 3

## Summary and conclusions

### Progress

- Within the **breast programme**, the **data return** for January 2015 showed:
  - 58% of new patients have been added to SDA pathway.
  - 1971 patients on the SDA pathway (1331 new patients and 640 existing patients).
  - Consistent increased usage of the SDA pathway from wave 1 demonstrates confidence in the system - 35% wave 1; 41% wave 2; 58% wave 3.
  - 1053 new patients (53% of all patients on SDA) had a HNA compared to 476 (47% in wave 2).
  - 503 attendees at health and well-being events across the five Trusts since May 2013.
- Compared to wave 1, more patients with breast cancer in wave 3 indicated that they have been seen on time; that their mammogram appointments happened at the scheduled time, and that their appointments were the right length of time.
- Within the **prostate programme**, it was noted that:
  - Whilst the programme has been slower to embed, there has been progress across all five Trusts. There are now patients moving onto different pathways in each Trust.
  - Although the numbers are small, they are being aided by an increase in CNSs, and by the implementation of the PSA IT tracking system.
- Whilst focus group participants in wave 3 (i.e. patients with breast and prostate cancer) were generally not familiar with the website the NICaN survivorship website monthly hits have increased from 191 per month to 676 per month; since January 2014. The total hits since its development to Dec 2014 is 14,500.

### Impacts

- **Patients with breast cancer** were happy with the support they receive from their CNS, the rapid access system and the review mammography system.
- Overall, 87% of patients with breast cancer surveyed in wave 3 were satisfied with their after-care:
  - 80% received enough information about support services in wave 3 compared to 51% in wave 1.
  - 91% received enough clinical support in wave 3 compared to 83% in wave 1.
  - 79% were made aware of the importance of lifestyle changes in wave 3 compared to 45% in wave 1.
- Patients with breast cancer identified four key features of the programme:
  - the role of their CNS;
  - the rapid access system;
  - fewer review appointments, and
  - the review mammography system.

- Whilst there is less available evidence on the impact of the programme on **patients with prostate cancer**, due to the smaller numbers of evaluation participants, some observable impacts were beginning to emerge in wave 3, such as patients reporting less anxiety due to having direct access to their CNS and more confidence in managing their care.
- It was suggested by some wave 3 patients with prostate cancer that they could have been better signposted to additional support services:
  - Only a few of these six patients in wave 3 had attended health and wellbeing events, although most participants expressed a desire to do so.
  - Some patients with prostate cancer stated that more attention could be given to support them to manage the emotional impacts of cancer.
- Patients with prostate cancer, who participated in wave 3, identified two key features of the programme – their CNS and the support groups organised by Macmillan.
- **Wider stakeholders** agreed that perceptions about aftercare have changed for the better and that there is now a greater focus on survivorship, which is welcomed.
- Wider stakeholders identified four key features – the recovery package, clinical team support, the adaptability of the programme and the health and well-being events.

### Challenges

- The main challenges to achieving ongoing improvements in patient aftercare experience were identified as:
  - changing the mind-set of patients;
  - maintaining a patient focus, so that individual patients' needs are met as well as targets;
  - obtaining full support from Trust staff, clinicians in particular, and
  - mobilising the necessary resources to enable the programme to be sustainable.

### ***3. Improving resource utilisation***

*“Capacity has been released for the right reasons and there is a more effective and higher quality service for patients now. Consultants can now spend more time with patients and better explain the situation.”*

(HSC Trust staff)

## Introduction

An important aim of the TCFU programme is to create a more efficient system so that capacity can be focused where it should be. Historically, there has been duplication in breast follow-up practice, with patients being seen by their surgeon and oncologist. In addition, inefficiencies are exacerbated by the fact that often these appointments add little or no value for either the patient or the doctor – these are the so called “empty appointments.”

This section sets out the findings from the evaluation in relation to the impact of the TCFU programme on resource allocation and utilisation. The findings are drawn from the data return, Trust staff focus groups, and from interviews with wider stakeholders. The section is structured under progress, impact, and challenges.

## Progress

### Breast programme

Baseline data for 2010/2011 showed that 995 patients were on backlog waiting lists for oncology breast review clinics across four of the five HSC Trusts (excluding the Southern Trust). This resulted in 63 additional oncology clinics being scheduled for that year. In addition, in terms of the surgical experience, it was noted that recurrences most frequently occurred outside of planned reviews and were picked up either by the patient or as a result of their mammogram.

The table below shows the profile of review appointments for the first five years of aftercare for a patient on the traditional follow-up model. In total, a patient on the traditional follow-up model will have 11 review appointments over five years.

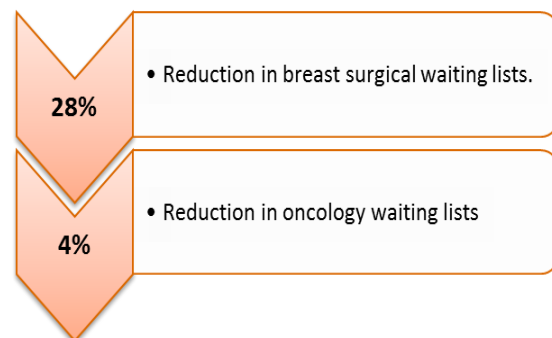
**Table 3.1: Five year traditional follow-up model review pattern**

Traditional follow-up model review pattern	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Number of times patient is reviewed by surgery	1	1	1	1	1	5
Number of times patient is reviewed by oncology	2	1	1	1	1	6
<b>Total number of times patient is reviewed over 5 years</b>	<b>3</b>	<b>2</b>	<b>2</b>	<b>2</b>	<b>2</b>	<b>11</b>

Based on CaPPs data (2011), there was 1461 new breast cancer diagnoses in NI in 2011. If 30% of all new patients are moved to SDA (i.e. 438 patients/year), they would require the equivalent of 1927 review appointments over five years of care, whereas the same group of patients would require the equivalent of 4818 review appointments in any given year of care if they were to remain on the traditional follow-up model. This is a saving of 2891 appointments per year.

In reality the data return from Trusts involved in the programme for January 2015 showed a 28% reduction in breast surgical waiting lists since November 2012; this is a total reduction of 2724 appointments across all Trusts, with a reduction in Belfast Trust of 555 appointments; Northern Trust: 602; South Eastern Trust: 182; Southern Trust: 839, and Western Trust: 546 (please see table 1 in appendix 4). Patients were moved on to the new pathway from May 2012 in the Western Trust and in the remaining Trusts this took place from September 2012. There has been a 4% reduction in oncology waiting lists across all five Trusts since November 2012, with a saving of 228 appointments (please see table 1 in appendix 4).

This provides further evidence of the progress that has been made in reducing the need for follow-up appointments. Moreover since November 2012 there have been 100 less patients waiting past their clinically



Source: Data collated through a desk based review of waiting list figures from all five Trusts (carried out in January 2015)

indicated appointment time for oncology breast review. Table 3.2 below demonstrates the reductions. It also must be noted that since 2012 there have been no additional oncology waiting lists, compared to the 63 additional oncology waiting list initiatives in 2010/2011 (as per Belfast Trust).

**Table 3.2: Oncology review waiting lists**

	<i>Appointments in the future</i>	<i>0-3m</i>	<i>3-6m</i>	<i>6-9m</i>	<i>9-12m</i>	<i>TOTALS</i>
<i>Nov-12</i>	2810	583	211	162	22	3788
<i>Dec-14</i>	2713	483	254	141	0	3591
<i>Difference</i>	↓97	↓100	↑43	↓21	↓22	↓197

Source: Data collated through a desk based review of waiting list figures from Health and Social Care Board (carried out in January 2015)

Data from evaluation participants in wave 3 of the programme noted that improvements in resource allocation and utilisation for the breast programme have been facilitated by appropriate systems being in place and dedicated resources being allocated. Figure 3.1 provides a summary of what has enabled progress in achieving better use of resources within the breast programme.

**Figure 3.1: Enablers to improving resource utilisation - breast programme**



Source: Data collated through the interviews and focus groups conducted in wave 1 and wave 3 with Trust staff, wider stakeholders and patients; as well as the patient surveys conducted in wave 1 and wave 3

Underpinning the success of these developments in breast care was the early agreement of SDA pathways in 2012 and the fact that review mammography systems were operational from August 2012. The Western Trust had the system in operation prior to the TCFU programme. In addition, Patient Administration System (PAS) codes were developed and operational in early 2013, and agreement was secured on rapid access via the CNS. These early developments facilitated a standardised practice across the region, and have encouraged the acceptance of a multi-disciplinary approach to determining a patient’s ability to self-manage.

**Prostate programme**

In 2013, baseline information was gathered across all five HSC Trusts for 250 patients who were diagnosed with prostate cancer in 2008, in order to ascertain the number of surgical appointments and oncology appointments. The data demonstrated variation across Trusts with no apparent uniformity of practice. In 2013, five Trusts undertook an audit to ascertain the numbers of patients assigned to watchful wait and active surveillance pathways. Utilising this data, NICaN undertook a modelling exercise for a ten year follow-up period. With 369 new patients assigned to the watchful wait or active surveillance pathways each year (based on current rates), there would be nearly 13,000 review consultant appointments required per year by year ten. It was noted that with the introduction of nurse led follow-up, the need for consultant appointments could be significantly reduced.

Unlike the breast programme, the development of the prostate programme has been slow. Consequently, there has been slower progress in achieving improvements in resource allocation and utilisation. However, over the course of the evaluation, wider stakeholders have agreed on the potential for the programme to change levels of follow-up and, with the development of new CNS roles, progress is being made across all Trusts.

It has been consistently noted that the nurse-led prostate pathways, which have been in operation for some time in the Western Trust, are key enablers to improving resource allocation and utilisation within the prostate programme. A report on the optimisation of the PSA IT tracking system in the Western Trust demonstrated that

if all suitable patients moved onto the PSA IT tracker in year three of their aftercare then a total of 1,896 consultant outpatient clinic appointments would be released (if there were no nurse-led clinic reviews), *(please see detailed report in appendix 5)*.

There has been good progress across all of the Trusts in terms of resourcing, with a number of Trusts now securing more CNS posts through a variety of funding sources. In particular, the Northern Trust has recruited two B6 project nurses in post, which has meant the commencement of a nurse led telephone follow-up pilot and further progress on the implementation of the PSA IT tracking system.

The key to achieving efficiency and resource utilisation, as identified by Trust staff in wave 3 of the evaluation, is the implementation of nurse led prostate pathways, and the administrative staff who free up the time of the CNS. In the Western Trust the addition of an administrative post to register all patients under remote surveillance has released 0.4 WTE Band 7 CNS time *(please see detailed report in appendix 5)*. These findings are illustrated in Figure 3.2.

**Figure 3.2: Enablers for improving resource utilisation- prostate programme**



Source: Data collated through the Trust staff focus groups in wave 3

## Impact

### Breast programme

During wave 3 of the evaluation a range of participants provided their views on the impact of the programme on improving resource utilisation. Demonstrable impacts included more time being available for clinicians with more complex patients. These findings are illustrated in Figure 3.3.

**Figure 3.3: Impact on improving resource allocation – breast programme**

<b>Clinician’s time can be used more efficiently and effectively...</b>	<i>"Clinician time is still used up but now it is quality rather than quantity. Some patients are complex and need more time." (HSC Trust focus group participant)</i>
	<i>"Breast reconstruction patients had been seen in a clinic review slot which was quite short but now they are being seen by surgeons who have more time for discussion which is needed for these patients." (HSC Trust focus group participant)</i>
	<i>"There has been a reduction in duplication and patients are now in the right place at the right time." (HSC Trust focus group participant)</i>
<b>Reducing the need for routine review appointments releases capacity and frees up waiting lists...</b>	<i>"It makes more sense not to be clogging up the system with routine follow up appointments, when these didn't add any value to the clinician or the patient...so releasing capacity should lead to re-investment of resources..." (Project team interviewee)</i>
	<i>"It certainly gives an oppportunity for people to have a longer consultation and it will hopefully free up waiting lists. One of the big things that was happening was the review appointments were behind schedule and we were getting phone calls to our help line. We still do get some calls, but there is the potential that when this programme is fully up and running these should reduce significantly." (Voluntary Sector interviewee)</i>

Source: Data collated through HSC Trust staff focus groups and wider stakeholder interviews conducted in wave 3

It is encouraging to note that 92% of patients with breast cancer, who responded to the survey in wave 3, indicated that they were satisfied that their mammogram appointments happened at a scheduled time each year.



In addition to the positive impacts at a secondary care level, GPs also highlighted the benefits of the TSR in terms of maximising resources at primary care level, in that GP practices no longer have to source information from a number of documents, which is time consuming and less reliable. Notably, 72% of patients with breast cancer, who responded to the survey in wave 3, were satisfied that there was good communication between the hospital and primary care.<sup>27</sup> This compares to 61% of patients in wave 1, all of whom were on the traditional model of follow-up (*please see charts 4 and 19 in appendix 3*).

In addition, the GPs interviewed as part of the evaluation reported that, to date, the programme had not had any adverse impact on workload, although currently each GP will only have between two and five patients who are on the TCFU breast programme.

*“With the treatment summary record, the information is on one sheet. Previously in the past patients would have been up and down to hospital four or five times and we had to pick through all of the information. So it is much easier to draw together.” (GP interviewee)*

*“The impact for GPs in terms of workload has been virtually nothing. Each individual GP probably has no more than two to five patients on the programme. So there is not enough to notice the difference. I don’t anticipate any impact on workload for patients with breast cancer.” (GP interviewee)*

### Prostate programme

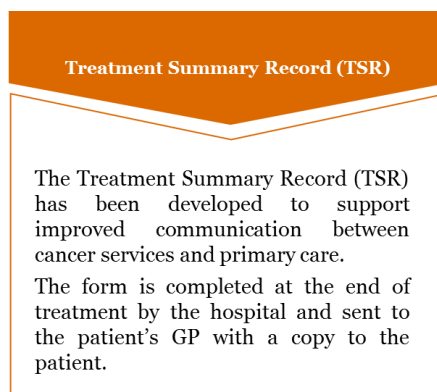
Throughout the evaluation, Trust staff have consistently identified the lengthy waiting times for review appointments as a negative feature of the traditional model of follow-up for patients with prostate cancer. This was restated by participants in wave 3 of the evaluation, who noted the potential for the programme to reduce waiting lists by releasing operational capacity through redesigned follow-up models. Anecdotal evidence was provided that this is beginning to happen. However, further embedding of the programme is necessary in order to provide more concrete evidence that this is taking place on a wider scale.

In terms of the impact of the prostate programme on GPs’ workload, it was noted that decisions still need to be made about the role of GPs, who may have concerns about having to interpret and manage blood tests for these patients.

*“The programme is likely to free up the consultant to concentrate on complex patients with a variety of health issues.” (Trust focus group participant, prostate programme)*

*“The project has had a big impact on releasing operational capacity by providing a part time band 6 CNS. (Trust interviewee, prostate programme)*

*“The workload may change for GPs when the prostate programme is fully implemented. There would be some concern if GPs were required to interpret blood results for these patients, although it is likely to be done via secondary care...” (GP interviewee)*



Source: Definition taken from the National Cancer Survivorship Initiative website

### Challenges

Staff at all levels within Trusts were committed to avoiding duplication of review and to reducing routine waiting lists and review backlog. Notwithstanding this commitment, a number of challenges were identified which relate to both the breast and prostate programmes. These centre on the need to sustain and build the momentum for the programme at individual Trust level, and on the need to mobilise appropriate resource in order to build on the progress made. It was noted that whilst the project managers have played a key role in building and maintaining momentum at an individual Trust level, some Trust staff felt that the programme is

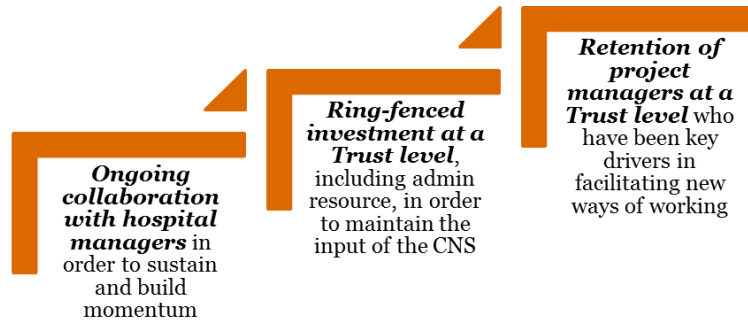
<sup>27</sup> 13% indicated neither/nor; 7% didn’t state a reply



not a key priority for management, and that once the project managers are no longer in post it might receive less attention.

In light of these concerns, some steps to success were suggested which, if taken on board, may enable the programme to maximise resource allocation and utilisation.

**Figure 3.4: Sustaining improvements in resource allocation and utilisation - Steps to Success**



Source: Data collated through focus groups and interviews conducted with Trust staff, wider stakeholders and patients in waves 1, 2 and 3.

Finally, some Trust staff were keen to point out that the programme should not be viewed as a cost saving exercise. Nonetheless, there was clear recognition that, if fully implemented, it can achieve a more efficient system of reviewing patients, and enable capacity to be focused where it should be.

*“Within the Trust the support from the lead nurse has been critical...They engaged with their senior colleagues within the Trust. There may be competing agendas and people may not appreciate the potential for it to deliver in terms of improved experience and cost effectiveness. Directors of cancer services need to be kept informed and on board.” (Project team interviewee)*

*“This programme is not about saving money; it’s about improving care and giving the right care to the people who need it. The programme is about patients and not about cost saving. But the necessary resources and drivers are needed in order for the programme to achieve what it set out to do.” (HSC Trust focus group participant)*

## Summary and conclusions

### Progress

For the **breast programme**, the **data return** for January 2015 showed:

- **2952 appointments have been released** demonstrating a significant reduction in waiting lists across breast surgical and oncology. This represents:
  - a **reduction of 2724** (28%) in breast surgical waiting lists across all five Trusts;
  - a **reduction of 228** (4%) in breast oncology waiting lists across all five Trusts, and
  - no additional oncology waiting lists initiatives since 2010/2011 when there were 63 additional waiting lists.
- In Trusts where implementation of the prostate pathways has progressed, benefits can be seen in release of consultant capacity. Belfast Trust, South Eastern Trust, Northern Trust and Western Trust have all seen progression of patients onto the new follow-up pathways.
- In addition, a report on the optimisation of the PSA IT tracking system in the Western Trust demonstrated that if all patients moved onto the PSA IT tracker in year three of their aftercare, then a total of **1896 Consultant outpatient clinic appointments would be released**.

At a **breast programme level**, the **key enablers** to improving resource utilisation for patient follow-up care were identified as:

- dedicated time for CNSs;
- careful selection and coding of SDA patients;
- centrally generated mammography system;
- administrative support to manage mammography, and
- efficient use of the TSR.

At a **prostate programme level**, the **key enablers** for improving resource utilisation were identified by wider stakeholders as:

- nurse led prostate pathways;
- administrative staff to free up time for CNSs, and
- the PSA IT Tracking System.

At a **primary care level**, GPs highlighted the benefits of the **TSR** in terms of enabling more efficient sharing of information.

### Impact

- The evaluation identified some **observable impacts** within the **breast programme**, such as:
  - clinicians' time being used more efficiently and effectively, and
  - a reduction in the need for routine review appointments, which has led to increased capacity and fewer waiting lists.
- There were **fewer demonstrable impacts at this stage of implementation within the prostate programme**. However:
  - Wider stakeholders were confident about the potential for the programme to reduce waiting lists with the implementation of the new follow-up pathways. There is evidence that this is beginning to happen within a few Trusts.
  - Decisions still need to be made about the role of GPs, some of whom have expressed concern about having to interpret and manage blood tests for patients with prostate cancer.

### Challenges

- The key challenges to achieving ongoing improvements in resource allocation and utilisation centre on maintaining the momentum of the TCFU programme at an individual Trust level, and on ensuring that appropriate resources are in place to sustain and increase progress.
- In order to overcome these challenges some **Steps to success** were identified:
  - ongoing communication with hospital managers;
  - continued ring-fenced investment, including admin resource, and
  - retention of the project manager posts, who are seen as key drivers.

## ***4. Enhancing the coordination and integration of care***

*“This programme has involved everybody at all levels, from strategic-commissioners to charities, and full involvement with clinicians, the Board, the Public Health Agency and other charities. There has been wide involvement and wide support at Trust level.”*

(Wider stakeholder)

## Introduction

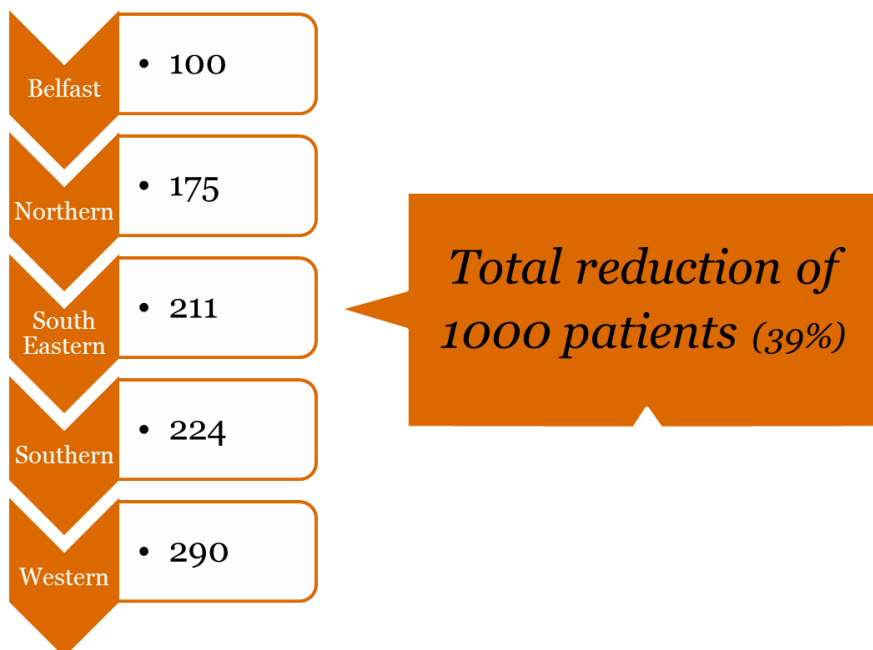
One of the aims of the TCFU programme is to enhance the coordination and integration of care. This aligns with Transforming Your Care (DHSSPS, 2011) which sets out a vision for an integrated health and social care service, with quality and outcomes remaining the determining factor in shaping services. Personalisation of care, prompt discharge, care closer to home, and enabling individual responsibility for health and wellbeing are among the central principles for change. The TCFU programme is based on a risk stratified model of care, involving self-care with support and open access, shared care, and complex case management delivered by a multi-disciplinary team.

The project team has worked closely with identified Trust teams, and organisations, to develop collaborative working arrangements and to provide support in order to ensure the success of the overall programme. Trusts have also established local steering groups with executive leadership, identified Trust leads, clinical leadership and primary care / LCG involvement. This section of the report sets out the extent to which the TCFU programme has enabled and facilitated improved coordination within the acute setting, and between acute and primary care, as well as between the statutory and voluntary and community sectors. The comments provided by wider stakeholders generally relate to the breast programme. The remainder of the section is structured around progress, impact and challenges.

## Progress

The data returns indicate that ongoing review of patients with breast cancer on surgical and oncology waiting lists is helping to avoid duplication between surgery and oncology, and thereby facilitating a more coordinated and joined up service. Work on avoidance of duplication between breast surgical and oncology reviews led to a reduction in all five Trusts with waiting lists reduced by 1000 patients. This represents a 39% reduction in duplication of review appointments and this is an increase on the 14% reduction recorded in wave 2 of this evaluation. Figure 4.1 below shows the reduction in dual speciality follow-up from November 2012 to January 2015 across all Trusts.

**Figure 4.1: Reduction in dual speciality follow-up from November 2012 – January 2015**

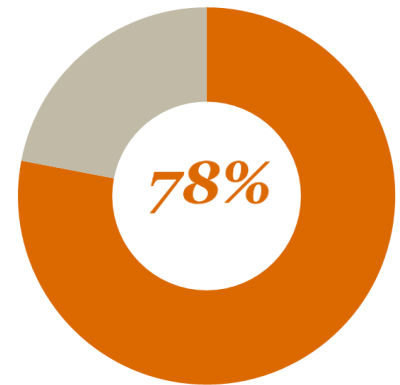


Source: Data collated through a desk based review of duplication appointment figures from Health and Social Care Board (carried out in January 2015)

## Impact

All wider stakeholders provided comments about the programme's impact on service integration and co-ordination. It was noted that the survivorship website had provided a mechanism for knowledge sharing between all stakeholders, including patients, although patients who participated in the focus groups appeared to have not utilised the website. The wave 3 survey carried out with patients with breast cancer indicated that 78% of respondents agreed/strongly agreed that the various aspects of their care were well coordinated; this is compared to 71% who strongly agreed/ agreed in wave 1. In addition, 71% of patients who responded to the survey in wave 3 felt that there was good co-ordination between the hospital and the primary care team about their treatment, and in wave 1 this figure was around 66% (please see charts 4 and 19 in appendix 3).

Figure 4.2 provides a summary of the views of wider stakeholders on the impact of the programme in facilitating improved co-ordination and integration of care within the hospital setting, between primary and acute care, and between primary care and the voluntary sector.



*78% of patients with breast cancer strongly agreed/agreed that the various aspects of their care were well co-ordinated.*

**Figure 4.2: A summary of the impact of TCFU on integration and co-ordination of care**

### Improved integration and co-ordination within the acute setting...

- The regional roll out of the programme has enabled a consistent and co-ordinated approach (Trust staff)
- The project manager has encouraged a greater emphasis on team working and has helped to manage any risks involved (Project team)
- The e-referral system has helped to support integration and coordination between the clinical teams (Trust staff)

### Improved integration and co-ordination between acute and primary care...

- The TSR has enabled improved collaboration between acute and primary care and it was believed that GPs would have greater confidence that effective communication systems were in place (Trust staff and project team)
- The TSR had created more uniformity between consultants. GPs no longer had to locate patient information from different sources. (GPs)
- Patients are being referred in a more co-ordinated way via the rapid access system (GPs)
- 76% of 26 GPs surveyed in wave 2 indicated that the use of the treatment summary letter process should continue, and the majority were positive about the content and information within the letter (GPs)
- It is valuable to have GPs being represented on the TCFU steering group (Project team)

### Improved integration and co-ordination between Trusts and voluntary sector...

- There are reports of more referrals to support groups (Trust staff)
- The extent and nature of involvement of voluntary and community groups may be dependent on existing relationship with Trusts. It was noted that the involvement of the voluntary sector has been most positive where a good working relationship existed prior to TCFU (Voluntary sector representatives)
- Locality groups are enabling Trusts to connect to the community and voluntary sector (Trust staff)
- There is the potential and willingness for greater involvement of voluntary and community groups who are often the key service providers in this area (Voluntary sector representatives)

Source: Data collated through focus groups and interviews conducted with Trust staff, wider stakeholders and patients in waves 1, 2 and 3.<sup>28</sup>

<sup>28</sup> Locality Groups are partnerships between statutory, voluntary and community organisations

## Challenges

Notwithstanding the positive impacts of the programme in enabling better integration and co-ordination of services, wider stakeholders identified some challenges which, if addressed, will lead to a more integrated and co-ordinated approach to the programme. These challenges can be summarised as: process challenges; communication challenges, and financial challenges. These are illustrated in Figure 4.3.

**Figure 4.3: A summary of TCFU challenges which are affecting the integration and coordination of care**

<b>Process challenges</b>	Structures and management systems within Trusts vary, which creates challenges for the co-ordination of the programme between Trusts
	Coding of patient information can present challenges for temporary staff, who are not familiar with the system
	The voluntary and community sector desire more involvement in the planning and implementation of the programme
<b>Communication challenges</b>	There is a need for better communication with GPs in order for them to fully engage with the programme
	There are reported differences between Trusts in the number of referrals made to voluntary /community organisations. This may be due to the existing relationships between some voluntary sector organisations and Trusts being less well developed.
<b>Financial challenges</b>	The future involvement of the voluntary and community sector in the programme is dependent on sufficient funding. For example as the programme expands, pressure may be placed on voluntary and community organisations as a result of increased referrals.
	Some voluntary organisations are struggling to attend health and well-being events, due to the financial costs involved in staffing, etc.

Source: Data collated focus groups and interviews conducted with Trust staff, wider stakeholders and patients in waves 1, 2 and 3.

Overall, it was felt that, as the programme principles are applied more widely, the approach of TCFU could contribute on a greater scale to achieving better integration and co-ordination of services, which will have benefits for both patients and staff.

## Summary and conclusions

### Progress

- The data return provided by each of the Trusts shows:
  - Since November 2012, there has been a **39% (100) reduction in duplication of review appointments** between breast surgical and oncology reviews.

### Impact

- 78% of patients with breast cancer who responded to the survey in wave 1 were satisfied that various aspects of their aftercare were well co-ordinated. This is compared to 71% in the wave 1 baseline survey.
- Trust staff believed that the survivorship website provides a useful mechanism for knowledge sharing between patients and wider stakeholders.
- Around three quarters of patients with breast cancer who responded to the survey agreed that the various aspects of their care were well-co-ordinated and that there was good co-ordination between the hospital and the primary care team about their treatment.

### Impact

- There is evidence that the programme has facilitated more effective communication and collaboration between acute and primary care, and the TSR has been key to enabling this. In addition, the rapid access system provides a more co-ordinated approach for GPs to refer patients back into the acute system.
- Some Trusts are referring more patients to support groups in the community. However, there is the potential and willingness for greater involvement of the voluntary and community sectors in the programme. It was noted that locality groups enable Trusts to connect with the community and voluntary sector.

### Challenges

- A number of challenges were identified which, if addressed, will lead to a more integrated and co-ordinated approach to the programme:
  - The structures and management systems within Trusts vary which creates challenges in terms of a co-ordinated approach.
  - Communication with GPs and voluntary and community groups could be improved.
  - Some voluntary organisations may face financial constraints in engaging with the health and wellbeing events.

## ***5. Learning from the programme***

*“In the absence of the programme, I think there would have been the potential for the system to become worse, as more and more patients were diagnosed and there were no additional resources - waiting lists were going to crack at the seams and something had to be done to manage this.”*

(Wider stakeholder)



## Introduction

This section of the report draws together the key learning from the programme in terms of what has worked well and what could have worked better at a strategic and operational level. The extent to which the programme is believed to be transferable and sustainable is also considered.

## What worked well?

A number of strategic enablers have been integral to successful implementation of the programme. In addition, some operational enablers within breast and prostate have been identified throughout the evaluation. These are outlined below:

### Strategic enablers

#### The endorsement of the programme

Underpinning the acceptability of the programme was agreement on the need for change and acknowledgement by wider stakeholders that the existing system was not sustainable, effective or efficient. There was also consensus that the programme was timely. One of the most important challenges faced by the project team was to ensure that the programme was acceptable to wider stakeholders. This was essential, in order to gain buy in. A key lesson learned was that a one size fits all approach to “pitching” the programme is not effective. An important lesson for the project team was to challenge themselves, when presenting the programme to different types of stakeholders, to acknowledge that clinicians respond to evidence about risks and benefits for patients and commissioners respond to assurances about safety, efficiency and effectiveness.

Whilst some clinicians were not fully on board in the early stages of implementation, these concerns have largely been overcome as the programme has evolved, and the majority of wider stakeholders are now on board and committed. Overall, a number of key drivers have worked together to enable the programme to become acceptable. These are set out in Figure 5.1.

**Figure 5.1: Key drivers to enabling the acceptability of the programme**

The need for change	Regional and coordinated approach	Mitigation of risks	Multi-disciplinary team
<ul style="list-style-type: none"> <li>Existing system was not sustainable</li> <li>Review appointments were not working for clinicians or patients</li> <li>Patients were not receiving satisfactory aftercare</li> </ul>	<ul style="list-style-type: none"> <li>Project managers coordinate the programme at Trust level</li> <li>Programme features are agreed and transferrable</li> <li>Guidance and support from the project team</li> </ul>	<ul style="list-style-type: none"> <li>Appropriate safeguards to ensure patients are tracked and monitored</li> <li>A strong focus on maintaining and improving the patient experience</li> </ul>	<ul style="list-style-type: none"> <li>Gaining buy-in from clinicians</li> <li>Trained and dedicated CNS</li> <li>Involvement of primary care and voluntary / community sectors</li> </ul>

#### A co-ordinated and regional approach

The programme required cultural as well as process change. Therefore, having ministerial approval, support from the Chief Medical Officer, and support from the HSC Board provided the reassurance and confidence that Trusts needed in order to implement new ways of working. In addition, a co-ordinated regional approach meant that the necessary accountability mechanisms were in place. The key learning in this regard is that cultural and process change is much less daunting for organisations if it is taking place at a regional level.

#### Dedicated regional funding

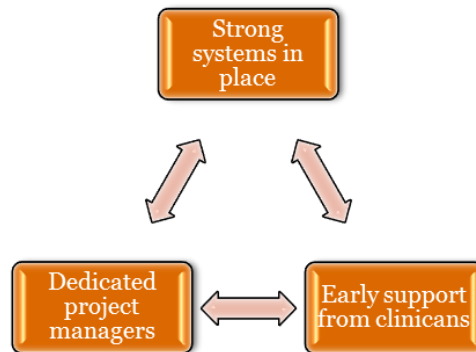
The funding secured by Macmillan was key to successful implementation, particularly in relation to the appointment of the project managers within each Trust. This enabled the programme to be rolled out to each of the five Trusts. These additional resources demonstrated confidence and commitment from the outset. In addition, the commitment

and involvement of Macmillan operating outside of the public sector system has provided external challenge to the HSC Board.

### ***Operational enablers***

Three key operational enablers were identified, as illustrated in Figure 5.2 below.

**Figure 5.2: Operational enablers**



#### **Role of the project managers**

The critical and positive role played by each of the five project managers was highlighted by wider stakeholders as being one of the most successful features of the programme. Project managers were seen as the key drivers, both in gaining buy in from clinicians, senior managers, and other staff, and in maintaining and building the momentum at an individual Trust level. In addition, the collaboration between project managers has facilitated knowledge sharing and support between Trusts.

#### **Early establishment of systems and processes within the breast programme**

One of the most significant factors in enabling the programme to be effectively and efficiently implemented was gaining approval and agreement on operational processes and systems. It should be noted that the more rapid progress within breast has largely been due to the systems and process that were put in place and agreed in the early stages of the programme. These included:

- developing and rolling out the review mammography system;
- agreeing the SDA pathways;
- establishing the rapid access system;
- gaining regional agreement on the five year follow-up;
- implementing the recovery package, and
- setting up the PAS codes.

These have individually and collectively enabled the breast programme to be implemented efficiently and effectively, albeit with some variations in progress between Trusts. They have also been key drivers in securing the support of clinicians, the CNSs, and patients.

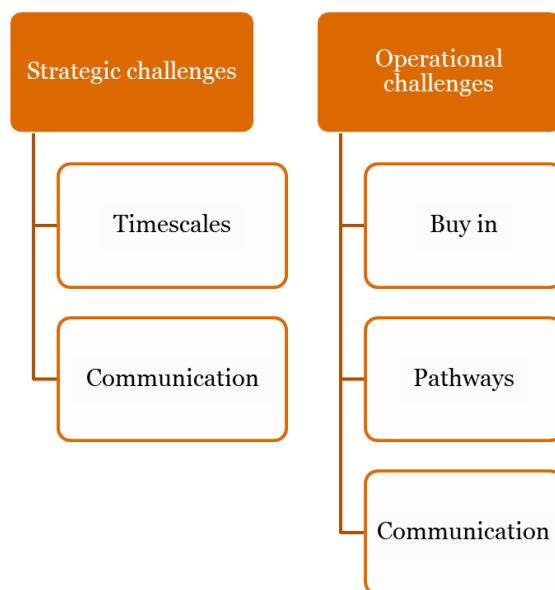
#### **Early support from clinicians within the breast programme**

Gaining support from clinicians has always been critical to the success of the programme. Generally, this was achieved early on within the breast programme, with good buy-in from most surgeons and oncologists, although there were some initial concerns within radiology. As noted above, clinician buy-in was enabled by the processes that were in place within the breast programme, such as the agreed pathways, and the further development, adoption and roll-out of the review mammography system which had been operating in the Western Trust for some time. It has been suggested that once clinicians are on board they can act as champions, advocating for the programme at a Trust level and beyond. The lessons learned in terms of gaining clinician support are important for expanding the approach to other tumour sites and more widely.

## What could have worked better?

Some strategic and operational challenges were identified, as summarised in Figure 5.3.

**Figure 5.3: Strategic and operational challenges**



### Strategic challenges

#### Less challenging timescales

There will always be competing agendas within health and social care. Underpinning the strategic challenges was the ongoing task of maintaining the profile of the programme and keeping it high on the HSC and political agenda.

One of the more specific challenges for the TCFU programme was the timescales, and there was general consensus by Trust staff, in particular, that these may have been challenging. In addition, alongside implementing the necessary changes at an operational level was the task of changing perceptions and culture.

It was noted that the programme was somewhat slow to get off the ground, due to the infrastructure not being in place, particularly within prostate. Some wider stakeholders suggested that a five year pilot programme might have worked better. However, conversely, other wider stakeholders felt that the time pressure involved may have created momentum for the programme, thereby enabling quicker progress in the long run. One member of the project team summed up the time pressures in that, “*there was a need to move fast enough to keep the momentum but slow enough to get people on board*”.

#### More effective communication

At an operational level, communication was facilitated by project managers who acted as gatekeepers both within and between Trusts, which worked well. However, some wider stakeholders noted that communication at a programme level could have been better, for example there could have been more communication with GPs and the voluntary and community sector. This would have enabled GPs and voluntary and community groups to better engage with the programme as strategic partners, which is what they desire.

### Operational challenges

Each Trust had its own operational challenges. However, overall, in terms of lessons learned, operational challenges identified by participants centred on the prostate programme. These focussed on less established CNS support and concerns from clinicians about engaging with the programme.

#### Pathways slower to develop within the prostate programme

The complexity of prostate cancer as a disease was noted by a number of evaluation participants, in that there is no standardised clinical approach to managing the disease, for example in relation to the management and tracking of PSA. In addition, unlike the breast programme, there were no established pathways at the commencement of the

programme. Development and regional agreement on the six pathways was a defining point for the prostate programme, but this did not take place until 2013.

### Clinicians slower to come on board within the prostate programme

The concern from some clinicians, particularly oncologists, about embracing the programme was noted throughout the evaluation. For example, there were varying degrees of experience and preparedness to working with CNSs amongst prostate clinicians. It is also important to emphasise that the approach of TCFU required a cultural shift as well as an operational shift on the part of clinicians, and it was acknowledged that this takes time. Notably, at this final stage of the evaluation, many clinicians who were previously sceptical are now on board with the programme.

### Communication to patients could have been better

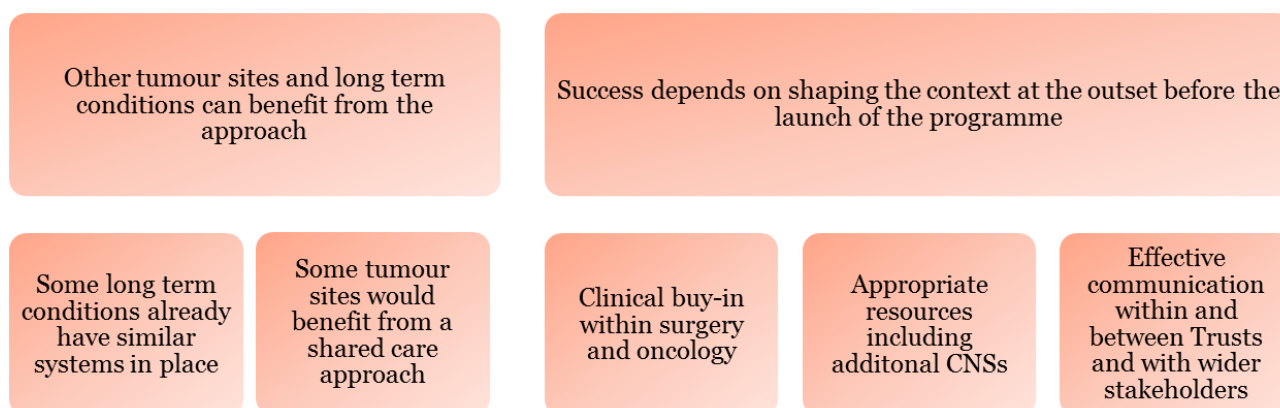
There was emerging evidence in wave 3 that clinicians and CNSs should be enabled to effectively communicate the programme to patients, so that patients can better understand the pathway and the features of the programme, as most patients who participated in the evaluation in wave 3 were not familiar with the terms being used to describe these features.

## Is TCFU transferable?

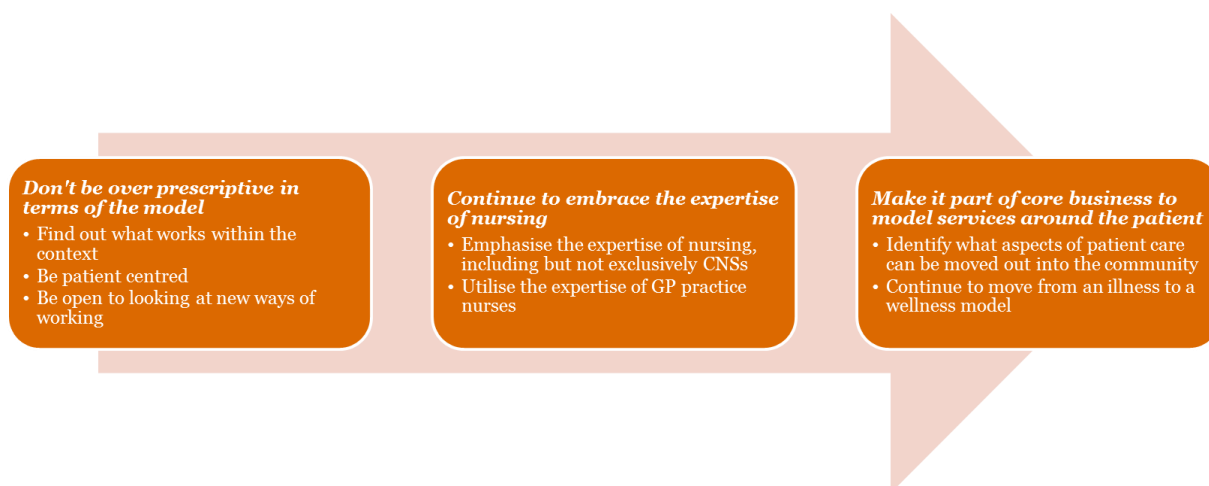
Notwithstanding the strategic and operational challenges that have been identified, it has been suggested throughout the evaluation that the TCFU programme is transformational. It results in individualised, holistic care, delivered in a shared environment by a multi-disciplinary team, all of which results in patients who are more empowered to be partners in their own care and to move on with their lives outside of the hospital environment. It is important to ask, therefore, whether the programme is transferable to other tumour sites, and to other long term conditions.

Overall, wider stakeholders were in agreement that the approach of the programme is transferable, both to other tumour sites, and to other long term conditions. Whilst there is consensus amongst wider stakeholders that the pre-existing models are not sustainable, and are not delivering effectively for patients, perhaps the key strategic lesson to emerge at this stage of the programme is that change takes time, and even more so if this involves changing mind sets. In addition, it needs to be noted that some long-term conditions may have similar systems in place and that it would be sensible to share good practice across programmes. In terms of the key operational lessons to emerge, these mirror those outlined in the previous sections: obtaining buy in; securing resources, and enabling effective communication. These views are summarised in Figure 5.4.

**Figure 5.4: Stakeholders' views on the potential transferability the programme**



Bearing in mind the above points, some suggestions for transferring the programme were identified by wider stakeholders. These centre on not being over-prescriptive, embracing the expertise of nursing in general, and on making sure that change is centred around the needs of the patients. These are outlined in Figure 5.5.

**Figure 5.5: Stakeholders' suggestions to support the transferability of the programme**

## *Is TCFU sustainable?*

In assessing the sustainability of the programme, it is important to consider the counterfactual – i.e. what would have happened in the absence of the TCFU programme. Three possible outcomes were identified, in the absence of the programme:

- The system could not have sustained the demand being placed upon it.
- Waiting lists would have become much worse.
- The patient experience would have been unsatisfactory.

Not surprisingly, therefore, there is a desire for the programme to be sustainable and the vast majority of wider stakeholders and patients expressed this view. The requirements identified by wider stakeholders in order for the programme to be sustained mirror those for transferability: adequate resource; stakeholder engagement, and ongoing and effective communication.

With the dedicated Macmillan funding coming to an end, it was noted that there is a need for ongoing financial commitment in order for the programme to be sustained and expanded at an individual Trust level. Most of the wider stakeholders felt that the programme was still in its early stages and that the dedicated staff resource should be maintained in order to build on the success and to fully embed the programme.

- In particular, the role of the project managers is considered critical to the sustainability of the programme as they are viewed as a consistent point of contact at individual Trust level.
- In addition, dedicated administrative support was highlighted. In this regard, given the efficiencies that the programme is beginning to achieve, it may be possible for Trusts to reallocate resources in order to address the concerns expressed.

There is also a need to take on board the learning from the programme in terms of bringing and keeping everyone on board, including patients, clinicians, and wider stakeholders such as GPs and the voluntary and community sector.

Finally, at a recent conference hosted by NICaN, three scenarios for the future of the programme were suggested:

- it could run out of energy;
- it could plateau, or
- it could become the “new normal”.

It is the view of the vast majority of wider stakeholders who participated in this evaluation that the TCFU programme should become the “new normal”.

With this in mind, a number of suggestions to enable the programme to move forward have been provided, and these are set out in Section 6.

## Summary and conclusions

### Key findings

- Enablers and challenges were identified at a strategic and operational level:
  - Strategic enablers included:
    - the acceptability of the programme;
    - a coordinated and regional approach, and
    - dedicated regional funding.
  - Operational enablers included:
    - robust systems and processes within the breast programme;
    - dedicated project managers in all HSC Trusts, and
    - achieving early support from breast clinicians.
  - Strategic challenges included:
    - challenging timescales, and
    - communication with GPs and the voluntary sector.
  - Operational challenges included:
    - pathways slower to develop within the prostate programme;
    - clinicians slower to come on board within the prostate programme, and
    - communication to patients could be improved.
- Overall stakeholders agreed that the programme is transferable, although it was acknowledged that some long term conditions already have similar systems in place and that some tumour sites would benefit from a shared care approach. It was suggested that successful transfer of the programme is dependent on three key factors:
  - appropriate resource;
  - buy in from all stakeholders, and
  - effective communication.

- In addition, in seeking to transfer the programme, it was suggested that it should not be over-prescriptive as a model, and that the wider expertise of nursing should be utilised, including General Practice nurses. In addition, any proposed change should centre on the needs of patients.
- It was noted by wider stakeholders that in the absence of the programme, the system could not have sustained the demands being placed upon it, and waiting lists would have become much worse. In addition, the patient experience would have been unsatisfactory.
- With this in mind, there was a strong desire expressed by all stakeholders for the programme to be sustainable. Similar to transferability of the programme, it was noted that sustainability will depend on three key factors: appropriate resources, buy-in from all stakeholders, and ongoing and effective communication.
- It was the overwhelming view of stakeholders that the programme should become the “new normal”.

## ***6. Areas for consideration***





A range of issues were identified by consultees for consideration as part of the future development of this and other similar programmes. These are set out below:

## Approach

**One of the key enablers in successfully implementing the programme has been the staff who worked at an individual Trust level:**

- ❖ It would be helpful if existing resources could be reviewed in order to find ways of deploying the necessary staff in order to sustain a workforce that can support the type of follow-up demonstrated by TCFU and in order to sustain and develop the programme within each HSC Trust.

**Many patients feedback very positively on the support they have received from the programme:**

- ❖ It is important to follow-up on the desire expressed by patients to attend health and wellbeing events, particularly patients with prostate cancer who have not recently been diagnosed and who expressed a strong desire to attend health and wellbeing events.
- ❖ The small number of patients with prostate cancer that participated in the evaluation in wave 3 indicated that they would value more emotional support to help them deal with their cancer diagnosis, which may include more signposting to additional services. It would be good in future to elicit the views of more patients with prostate cancer in particular.
- ❖ In addition, it would be helpful, to look at additional ways to provide reassurance to patients with breast cancer immediately after surgery, as some patients appear to be more vulnerable at this stage. Some patients with breast cancer may also require more signposting to manage the financial impacts of a cancer diagnosis.

**The approach of the programme has facilitated better communication between acute and primary care and in addition some Trusts are now working more with voluntary and community groups:**

- ❖ It would also be useful to build on the positive work with GPs and the voluntary sector by further exploring how they can have greater and more meaningful involvement, particularly in programme planning and implementation. At a basic level of involvement, it was noted that more information could be provided about the programme to GPs and the voluntary sector.
- ❖ It would also be helpful to review the capacity and capabilities of voluntary and support groups across each of the 5 Trusts to enable consistent engagement with the programme.

## Activity

**The activities of the programme have improved patients' experience of their aftercare, and have resulted in less duplication and reduced waiting lists:**

- ❖

PwC

- ❖ In order to communicate these positive results further and enable the programme to be transferred, it would be helpful to collate and disseminate more evidence about the effectiveness of the programme. For example, additional evidence comparing the experience of patients not on the pathway with those who are, and evidence demonstrating the benefits of new ways of working.
- ❖ Linked to the above it is important to continue to effectively share good practice through the work of existing forums and the NICaN survivorship website. This could be used to demonstrate the work of the programme.
- ❖ The rapid access system, the review mammography, and the PSA IT tracking system have been very effective in enabling the programme to be implemented. Robust systems, such as these, will enable Trusts to cope with the demands as the programme expands. It might also be helpful to seek to develop systems, in co-operation with clinicians, which will facilitate more integrated models of care.

## Acceptability

**The programme was endorsed by all stakeholders and it was acknowledged that the existing system was not sustainable, effective or efficient:**

- ❖ If the programme is to be rolled out more widely, there will be a need to continue to address the perceptions of cancer aftercare, so that it is understood as a long term condition that can be managed outside of the hospital context.
- ❖ In addition, in order to continue to engage and communicate with patients effectively, it would be helpful to work with clinicians and CNSs to review the terminology used to describe various features of Recovery Package, and the SDA pathway.
- ❖ The NICaN survivorship website is a very useful tool for patients. It is important to explore how patients, some of whom may be cautious about using the Internet, can be encouraged to make proper use of trusted sources, including the survivorship website and the online tools it contains.

**The programme has been successful in promoting and developing a self-management approach to managing cancer as a long term condition:**

- ❖ To build on this success, it should now be part of "core business" to model aftercare around the needs of patients, recognising that clinical need is only one need amongst many. The benefits of a holistic approach should be highlighted, with a focus on a "wellness" model, as opposed to an "illness" model.

*This document has been prepared only for Macmillan Cancer Support and solely for the purpose and on the terms agreed with Macmillan Cancer Support in our agreement dated 28<sup>th</sup> September 2012. We accept no liability (including for negligence) to anyone else in connection with this document. Third parties are advised that the information contained therein does not constitute professional advice or a substitute for professional advice. It should not be distributed or relied on in relation to any business or other decisions or otherwise and is not intended to replace the expertise and judgment of such third parties' independent professional advisers.*

*If you receive a request under freedom of information legislation to disclose any information we provided to you, you will consult with us promptly before any disclosure.*

*© 2015 PricewaterhouseCoopers LLP. All rights reserved. In this document, "PwC" refers to PricewaterhouseCoopers LLP (a limited liability partnership in the United Kingdom), which is a member firm of PricewaterhouseCoopers International Limited, each member firm of which is a separate legal entity.*