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Evaluation of the Transforming Cancer Follow-Up Programme

Wave 1 Evaluation Report

August 2013 – Final Report

Acknowledgements

The PwC evaluation team is 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 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 wave 1 of this evaluation.

We would also like to thank Trust staff who participated in focus groups, and everyone who has participated in interviews including the project team/ steering group members, the Cancer Survivorship Collaborative and GPs.

Finally we would like to thank the patients who participated in the evaluation who gave up their free time to contribute to the patient survey openly and honestly.



Assumptions and limitations

In undertaking Wave 1 of 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 and opposite.

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.
- Stakeholders have provided open and honest views, which are representative of others in their organisation, profession and/or sector.

Limitations

- This wave of the evaluation was undertaken relatively early in the lifecycle of the TCFU programme, therefore it was difficult to quantify the programme's impact, as the number of patients being moved to the SDA pathway is small.
- The TCFU programme in Northern Ireland is a regional strategic approach to transforming cancer services. 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 benchmark.
- Not all stakeholders were available to participate in focus groups when these were held – this mostly impacted on clinical staff working in Trusts. Therefore, sample sizes for Trust staff was slightly limited.
- The baseline patient survey adopted a postal approach, in which a sample of patients were sent the baseline survey and a reminder letter two weeks after the survey was sent. As with any postal survey, we were limited in terms of the number of reminders which could reasonably be sent to these patients, and thus responses are lower than what might have been possible using other approaches (online or telephone).
- A current control group of patients who were not being allocated onto the SDA pathway was not available (as these patients may still be undergoing treatment). Therefore, the baseline patient survey involved patients who had prior experience of the traditional follow-up model and who had been treated for breast cancer in one of the Trusts between 2008 and 2011. Survey results may be impacted by their recall of the service at this time.

Glossary of terms

Abbreviation	Definition
EAG	Evaluation Advisory Group
GP	General Practitioner
HNA	Holistic Needs Assessment
HSC	Health and Social Care
HSCB	Health and Social Care Board
LCG	Local Commissioning Groups
MDT	Multi-Disciplinary Team
NI	Northern Ireland
NICaN	Northern Ireland Cancer Network
NRES	National Research Ethics Service
PAS	Patient Administration System
PHA	Public Health Agency
SDA	Self Directed Aftercare
TCFU	Transforming Cancer Follow-Up

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Executive summary

Executive Summary – Introduction and approach

Introduction

PwC was appointed by Macmillan Cancer Support in September 2012 to conduct an evaluation of the Transforming Cancer Follow-Up (TCFU) Programme in Northern Ireland (NI). The TCFU programme is a partnership between Macmillan Cancer Support (Macmillan), the Health and Social Care Board (HSCB) and Public Health Agency (PHA), facilitated by NICaN.

The TCFU programme aims to improve the quality of cancer patients' post-treatment experience and promote health and wellbeing; reduce inefficiencies in hospital follow-up and streamline services; and enhance service co-ordination and integration.

The evaluation will be conducted in three waves between September 2012 and November 2014 and will evaluate the programme as it progresses. Wave 1 of the evaluation focuses on the breast cancer programme given that more rapid progress has been made at this point in time than in the prostate cancer programme.

Approach taken to this evaluation

To inform this evaluation report, we used a multi-faceted approach to stakeholder engagement, as follows:

- Desk review of data and relevant literature;
- Ten focus groups with Trust staff;
- Six interviews with the project team and steering group;
- A baseline patient survey, which was sent to 234 patients and completed by 115 patients (49.1% response rate);
- Six telephone interviews with members of the Cancer Survivorship Collaborative; and
- Six telephone interviews with GPs.

Executive Summary – Context for this evaluation

Context

Baseline information was gathered on 50 breast cancer patients diagnosed in 2008/09 from each of the five Trusts to ascertain the number of surgical appointments and oncology appointments each patient attended over the four year period. This showed that across all five Trusts, patients had an average of five surgical review appointments and six oncology review appointments over the four year period.

Based on the baseline information obtained from Trusts through their CaPPs systems*, there were 1,461 newly diagnosed breast cancer patients across NI in 2011. From this data, if 30% of all newly diagnosed breast cancer patients moved to the SDA pathway, it would have the

potential to release 2,150 surgical and over 2,500 oncology review appointments over a four year follow-up period.

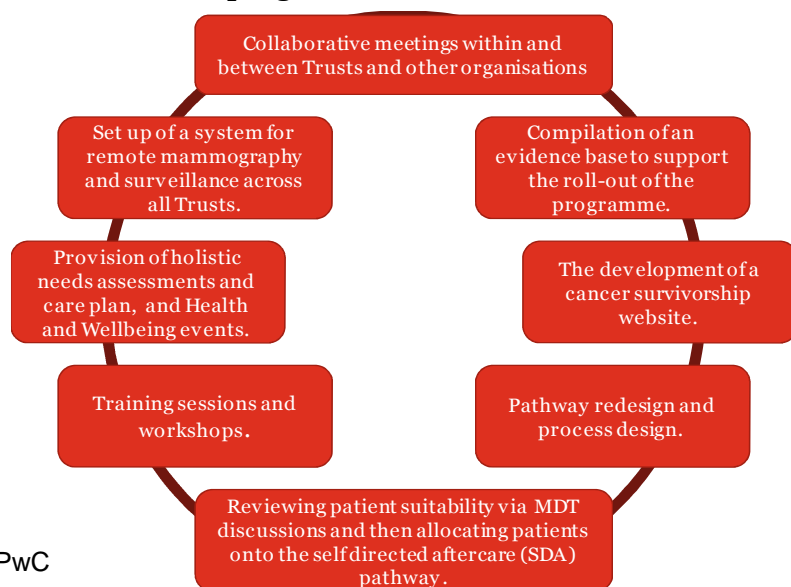
A patient survey was conducted to establish a baseline of patient views on the traditional follow-up model from those patients who were treated for breast cancer in one of the Trusts between 2008/2009 and 2011/2012. Key findings from the survey are shown below. Overall whilst the majority of patients agreed that they were supported in the clinical aspects of their care (82.6%), many indicated that the traditional model was not addressing their wider needs, such as the physical, emotional and financial impacts.

Did you receive the support you needed to manage...	% of patients who strongly agreed/ agreed
The clinical aspects of your cancer?	82.6%
The physical impact of cancer?	59.2%
The emotional impact of cancer?	44.3%
The financial impact of cancer	29.5%
The practical impact of cancer	40.0%
Lifestyle changes to maximise your health & wellbeing?	31.3%

Executive Summary – Outcomes and impact from the Breast TCFU programme to date (i)

Key activities to date

During 2012 and early 2013, the programme structure (regionally and in Trusts) and products for the SDA pathway were developed and agreed before patients were moved onto SDA. As of June 2013, 428 patients had been moved to SDA. This represents 35% of all newly diagnosed breast cancer patients being moved to SDA across the five Trusts. Focus groups with Trust staff indicated that whilst there are currently a relatively small number of patients moving onto the pathway, progress is being made and the pace and impetus is increasing. Beyond this, stakeholders cited a number of outputs, outcomes and achievements within the TCFU programme to date:



PwC

Activities – Health and wellbeing events

A total of 235 breast cancer patients attended cancer health and wellbeing events (across the Belfast, Northern and Southern Trusts), education days (in the Western Trust) and “Moving Forward” programmes (in the South Eastern Trust). These events are often co-created by a range of health professionals (including consultants) and wider representatives from the statutory and non-statutory sector, thus helping to promote the ‘shift left’ of services, away from traditional service provision in line with the ethos of Transforming Your Care. Feedback on these events highlighted the following:

Theme	Feedback received
Support from professionals	Information provided by Breast Care Nurses was very useful and all staff were well informed.
Information on services	Speakers and topics were relevant and informative. A large number of patients felt these events would have been more beneficial earlier in their treatment pathway.
Presentations / market stalls	Market stalls provided further advice, with the stalls on support & information and diet & nutrition most well attended.
Support from others	Attendees found it reassuring to meet others with the same experience and hearing other’s stories was reported as invaluable.

Executive Summary - Outcomes and impact from the Breast TCFU programme to date (ii)

Activities – the NI cancer survivorship website

This website was launched in November 2012 and has seen steadily increasing usage with a total of 2,326 views between Nov 2012 - May 2013. HSCNI views are not included in the figures due to firewall restrictions.

Stakeholder views on patient experience/ satisfaction

An overview of stakeholder views of the traditional follow-up model compared with the TCFU model based around the three main aims of this evaluation, are outlined below. At this stage of programme implementation, it is too early to provide tangible examples of outcomes and impact from the TCFU programme, however we have indicated in this report the progress which has been made to date.

Model	Themes identified by stakeholders – Patient experience and satisfaction
Views on traditional model	Trust staff described regular complaints from patients regarding: increasing waiting times for review appointments and a lack of value being added through review appointments. However staff also highlighted that many patients like the reassurance which annual review appointments provide.
Benefits of TCFU model	Trust staff identified a number of benefits such as: better educated patients; positive feedback from Health and Wellbeing events, empowering patients to self-manage; less travel for patients and less time spent waiting at clinics; reduced anxiety due to the provision of a Holistic Needs Assessment (HNA) and care plan; annual mammogram results being provided directly to the patient and their GP; and direct and rapid access to clinics if the patient has any worries in future.
Impact of TCFU model so far	All of the benefits listed above (with the exception of direct and rapid re-access) have already started to be realised for patients on SDA. However most of these impacts cannot easily be measured in terms of improved quality or cost-effectiveness at this stage.

Executive Summary - Outcomes and impact from the Breast TCFU programme to date (iii)

Stakeholder views on service integration and co-ordination

A number of Trust staff indicated that the traditional system was satisfactory in terms of integration across different areas of the hospital system (e.g. oncology, surgery, radiology), stating their reason for this being that it had been in place for many years. However others highlighted issues with surgical and oncology review appointments running together, when these are ideally meant to be spaced at six monthly intervals.

Some concerns were also raised about the lack of co-ordination across sectors. Trusts indicated that service co-ordination was starting to be observed within the TCFU model, through patients being identified and moved onto SDA and participating in Health and Wellbeing events which also involve primary care and the Third Sector.

“The new pathway will point people in a direction that they need to be pointed and so it’ll take less appointments to get to the person you need to see. If I’m sick, you want to be seen by the right person at the right time in the right place. I think this programme could deliver this.” (HSC Trust staff)

Stakeholder views on efficiency and resource utilisation

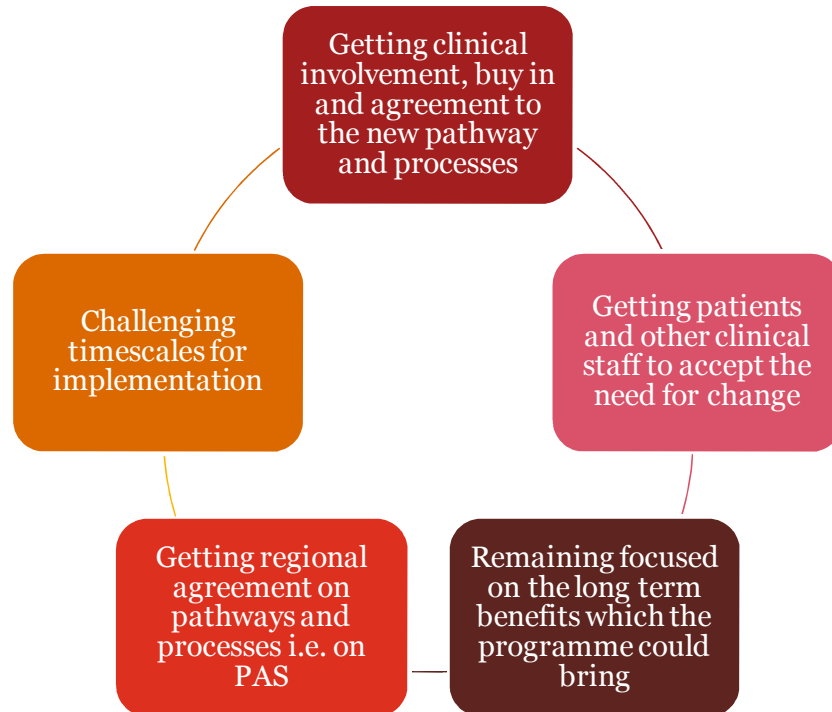
The main issues raised by all stakeholders in terms of efficiency and resource utilisation were around: duplication of appointments (particularly between surgery and oncology), delays in review appointments, and mammograms having to be repeated due to sub-optimal scheduling of various clinic appointments.

A number of positive aspects associated with the TCFU programme were recognised, such as: clinic space being released for new patients or more complex patients; being able to provide longer appointment slots; and the potential for reducing the need for extra ad-hoc clinics. To date, Trusts have not yet realised the impacts of additional clinic space, clinics being released or longer slots. This is because in most instances, patients across Trusts are just starting to be moved on to SDA. However there has been a reduction of 220 patients who were duplicated on both surgical and oncology review waiting lists across four of the five Trusts.

Executive Summary – Reflections on the process

Challenges associated with implementation

Those who took part in the evaluation were asked for their views on the main challenges of implementing the programme so far. These are shown in the diagram below.



These barriers have largely been overcome through the agreement of criteria for patients who will be moved to the SDA pathway, one of which was the development of regional Patient Administration System (PAS) guidance, and also through ongoing communication at a variety of levels. Clinical involvement has been secured for the breast programme, although it remains a challenge for Trusts to ensure that all clinicians are on board with the changes.

Critical success factors

In terms of critical success factors, HSC Trust staff in particular were keen to highlight the role which the TCFU Project Managers have played in driving the programme forward. Linked to ongoing pressures around timescales, staff indicated that ongoing support from Project Managers would be critical to future success.

Executive Summary – Learning from the TCFU programme to date

Learning from the programme to date

Stakeholders who took part in the evaluation highlighted the following as key learning from the programme to date:

The need to have clear action plans and deadlines, both at regional levels and within each Trust, which are actively managed	Involvement of a wide range of staff from an early stage (e.g. not just staff in cancer services, but also those in elective surgical care)
The need for good communication between clinical and administrative staff, to promote clarity as to which patients are going on the SDA pathway	The need for having people with the right skills to lead change going forward

Overall views from HSC Trust staff on the programme

Views from the range of stakeholders on the TCFU programme were largely positive, and all agreed that progress is now being made at an increasing pace. This can be seen from the findings of a word association exercise, completed by staff who took part in focus groups. These staff were asked to choose three words from a list of 20 which they felt best describes the progress of the TCFU programme in their Trust at that time. The words which were most commonly chosen were:

- Progressing (67% of staff);
- Patient-centred (35% of staff);
- Challenging (32% of staff);
- Complex (27% of staff); and
- Transformational (25% of staff).

Executive Summary – Areas for consideration (i)

Stakeholders highlighted seven areas for consideration, as shown in the table below and overleaf. We have also set out some suggested steps for moving forward with each of these areas.

Area	Moving forward...
Communication	<ol style="list-style-type: none"> 1. Ongoing communication is required across the healthcare system to highlight the rationale and benefits of the programme for all cancer areas. This will help in achieving clinical buy-in and support for the programme as it rolls out to other cancer sites and potentially to other disease areas. 2. Further communications to GPs should enhance their understanding and support for the programme.
Patient, service user and public expectations	<ol style="list-style-type: none"> 3. The aims and objectives of the programme should be communicated to current patients and those affected i.e. wider family, carers and the general public. This would help in setting expectations around follow-up care in the future, and would support clinicians in ‘selling’ the programme and concepts to patients and the public.
Project timescales	<ol style="list-style-type: none"> 4. An extension to the timescales would help to promote full, high quality and sustainable implementation of the programme in these two cancer sites, and could help in rolling the programme out to other sites.
Ongoing support for implementation	<ol style="list-style-type: none"> 5. Ongoing staff resources - particularly the TCFU Project Managers - are likely to be required to support implementation. 6. There will also be a need to continually monitor the workload of administrative staff and Breast Care Nursing staff, to see if assumptions around the number of patients who re-enter the system from SDA are proving accurate, and whether workload is manageable.
Clinical leadership	<ol style="list-style-type: none"> 7. In order to smooth the process of full implementation of the breast programme, and potentially enhance the roll-out of the programme to other cancer sites, clinical leaders should be more visible in each cancer site area in each Trust, and at Steering Group level.

Executive Summary – Areas for consideration

Area	Moving forward...
Holistic Needs Assessments & care plan	8. It would be worthwhile to examine what is working well or less well in each Trust with regards to HNA and care planning in order to identify good practice, and roll out an agreed approach on a regional basis. This would include agreeing timings for undertaking HNAs and care plans with patients on their cancer pathway.
Health & Wellbeing events	<p>9. Events should be continued and extended where possible. There may be benefits in extending these to wider groups of patients to promote self-management, such as those who are still within the traditional model, or have been recently discharged after five or more years follow-up.</p> <p>10. These events should be formally co-created (on an ongoing basis) across the key stakeholder groups including primary, secondary and voluntary sector organisations. There were suggestions that these events need to be an integral part of the care pathway and should be based in the community to promote self-management outside of the acute setting.</p>

Introduction

1

A partnership approach has been adopted to implement the TCFU programme, in order to enhance the effectiveness of the cancer follow-up system...

PwC was appointed by Macmillan Cancer Support in September 2012 to conduct an evaluation of the Transforming Cancer Follow-Up (TCFU) Programme in Northern Ireland (NI). The TCFU programme is a partnership between Macmillan Cancer Support (Macmillan), the Health and Social Care Board (HSCB) and Public Health Agency (PHA), facilitated by NICaN.

There is 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. A recent paper¹ highlighted 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' needs² and women have reported the increasing gap of their six monthly review appointments has been cause for concern and worry³ leading to interference in returning to everyday life⁴. While extensive evidence exists to support the promotion of a healthy lifestyle, this is rarely incorporated into the current model of follow-up¹.

It is within this context that the TCFU Programme in NI was developed in the five Health and Social Care (HSC) Trusts.

The TCFU Programme has initially taken forward two regional projects – one focused on breast cancer and one focused on prostate cancer; with the learning from these cancer sites expected to be applied to other cancer sites in the future.

The TCFU programme aims to improve the quality of cancer patients' post-treatment experience and promote health and wellbeing; reduce inefficiencies in hospital follow-up and streamline services; and enhance service co-ordination and integration.

A NICaN workshop in 2009 for patients and carers represented a significant driver for the TCFU programme with patients feeling "*aftercare is an after-thought*" and the need to radically improve aftercare services⁵.

In April 2010 professionals echoed this in 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.*"⁶

1. 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.cancerri.net/publications/developingnewfollowuppathwaysforpeoplewithbreastcancerareviewoftheevidence> (Accessed 19th June 2013)

2. 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.

3. 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.

4. 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*

5. Henderson, L., Johnston, G., Mills, M., Monteverde, H., McCulla, J., Hully, M., Campalani, S. (2009) *Beyond Cancer - Conference Report* <http://www.cancerri.net/publications/transformingcancerfollowupearlyworkshops> Accessed 26th June 2013.

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

Wave 1 of this evaluation seeks to provide an assessment of the impact of and learning from the new model of follow-up for breast cancer patients...

The evaluation will be conducted in three waves between September 2012 and November 2014 and will evaluate the programme as it progresses. Across the three waves, the evaluation will focus on both breast cancer and prostate cancer patients, in order to capture the learning from the project to inform future phases. However, this wave (wave 1) of the evaluation focuses on the breast cancer programme given that more rapid progress has been made at this point in time than in prostate cancer programme.

The purpose of the evaluation is to provide an independent and robust assessment of the impact of, and learning, from the new models of follow-up on: patient experience and satisfaction, service integration and resource utilisation. The specific objectives and key questions which the evaluation aims to address are shown in the diagram below:

Key Questions

Outcomes/impact:

- To what extent have the new models improved patient experience and satisfaction with the care and support they receive post-treatment?
- To what extent have the new models enhanced service integration and coordination?
- To what extent have the new models improved resource utilisation and do they provide more efficient ways of working (are they cost effectiveness compared to current practice)?

Objectives

- Provide regular findings that help to test whether the new models help achieve better outcomes for people with cancer and better resource utilisations.
- Draw out evidence and lessons learned on what works (and doesn't work), for whom, why and in what circumstances - to shape the development of the project and inform future phases.
- Work collaboratively with the project team and pilot sites, and be flexible in adapting the approach and methodology if the requirements and the scope/timing of the project change.

Key Questions

Process/learning:

- What factors are critical to the success of the projects and why? What circumstances enabled the projects to achieve their outcomes?
- What are the main challenges for the projects and how were these overcome? What were the barriers to achieving outcomes?
- What were the key lessons learnt through the process?
- What are the recommendations for future phases of the TCFU Programme?

Approach to wave 1 of this evaluation

2

We have used a multi-faceted approach to stakeholder engagement...

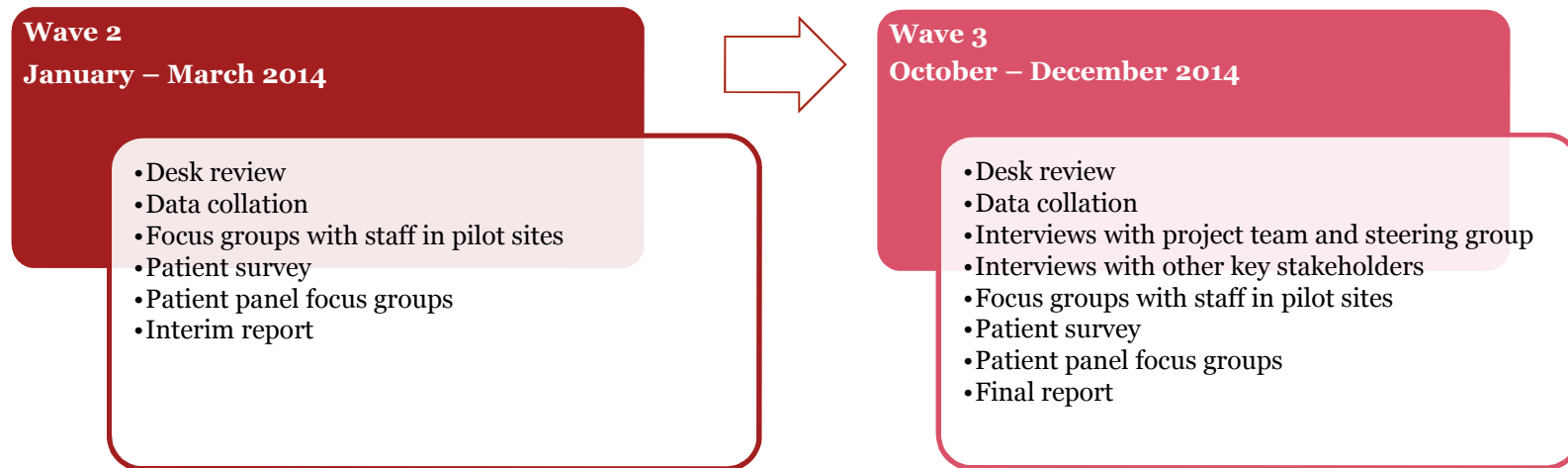
The figure below outlines the approach used for wave 1 of the evaluation which included a wide range of stakeholders involved in, or connected with the programme.



Our approach to this evaluation has been approved by each Trust, the Evaluation Advisory Group and in line with NRES guidance...

In line with guidance from the National Research Ethics Service (NRES) ethical approval was not required to conduct this evaluation, given that this fits well with NRES's definition of "service evaluation"¹. PwC then discussed and agreed our approach with the five Trusts liaising with those responsible for research/ evaluation within each Trust. All Trusts agreed that ethical approval was not required.

An Evaluation Advisory Group (EAG) was also set up to provide ongoing advice and guidance to the evaluation team on the approach, evaluating tools and reports. The evaluation has been commissioned as a formative evaluation over a two year period, so that findings can be regularly reported on and shared to help the development of the project. At this stage the plans for waves 2 and 3 are shown in the diagram below. However, these are subject to change as the programme evolves.



1. According to NRES a service evaluation is designed and conducted solely to define or judge current care, defines the standard achieved by the service, involves the analysis of existing data but may include administration of interview or questionnaire and does not require Research Ethics Committee (REC) approval. 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 18th June 2013]

Context

3

“The rationale [for the TCFU programme] is really to streamline patient follow-up to ensure that patients are not coming for needless follow-up appointments which would impact on both the patient and the clinic space, therefore allowing more clinic space for [new] patients”.

(HSC Trust staff member)

The TCFU programme has a clear and well understood rationale, particularly in secondary care, and is focused on helping survivors overcome the effects of cancer...

The number of people living with cancer is growing annually and within Northern Ireland it is estimated that around 70,000 people¹ are living with cancer. Whilst surviving cancer is a cause for celebration, when people have finished treatment they often have difficulties returning to normal life and may experience both physical and emotional effects which require significant life adjustments².

Studies indicate that current systems for breast cancer follow-up are ineffective in detecting recurrence, and research has queried both the value of the diagnostic test and routine check-ups in detecting recurrence³. Whilst there is extensive evidence to support the promotion of a healthy lifestyle and physical activity in cancer survivors, this is rarely incorporated into the current model of follow-up⁴.

The TCFU programme aims to help cancer survivors overcome the physical and emotional effects of cancer to enable them to lead as healthy and normal a life as possible through Self-Directed Aftercare (SDA).

The products for SDA includes: education and information for patients; holistic needs assessment and care plan, treatment summary records, GP letters to inform them of the changing system, health and well-being events and local processes to support rapid access back into the system.

Throughout the engagement activities undertaken for this evaluation, stakeholders demonstrated a clear understanding of the rationale for the programme with the most commonly cited statements shown below. Overall, awareness was highest amongst Trust staff in secondary care, with both clinical and administrative staff having a detailed understanding of the programme. Within the Third Sector, members of the Cancer Survivorship Collaborative also had a good understanding of the overarching principles of the programme, though in less detail than Trust staff who are delivering the programme on a day to day basis. Finally, understanding of the programme was lower in primary care, based on discussions with Macmillan's GP facilitators (see slide 48 for further details).

To reduce needless appointments

To reduce waiting lists and make sure review appointments happen on time

To empower patients to self manage their condition

To provide better education and information for patients

To move cancer towards a chronic disease model

1. Donnelly, D. (2013). *Living with and beyond cancer - A report on cancer prevalence in NI 2010* NI Cancer Registry <http://www.qub.ac.uk/research-centres/nicr/publications/nireports> Accessed 26th June 2013.

2. NICaN, Macmillan (2009) *Beyond Cancer*, [Conference Report October 2009]

3. 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*

4. Thompson, J., Mills, M., Henderson, L. and Lynas, C. (2013) *Developing new follow-up pathways for people with breast cancer: A review of evidence*

From a review of a 'baseline' group of patients, on average each had received five surgical reviews and six oncology reviews in a four year period...

Baseline information was gathered across each of the five HSC Trusts for 50 patients who used breast cancer services between 2008/ 2009 and 2011/ 2012 to ascertain the number of surgical appointments and oncology appointments each patient attended over the four year period. The figure of 50 patients was agreed by the Lead Oncologist and Lead Surgeon together with the NICaN team and agreed by the Trust TCFU Project Managers and Cancer Managers as a reasonable sample of patients at Trust and NI level, without making the task of gathering baseline information too onerous. The table below gives an overview of the range and average number of surgical and oncology appointments for patients in each Trust.

It is important to note that where there are higher numbers of appointments, this often relates to complex cases from either a surgical or oncological perspective. However despite this, the data demonstrates variation across Trusts with no apparent uniformity of practice.

Trust	Surgical appointments			Oncology appointments		
	Range	Mean	Median	Range	Mean	Median
Belfast	1 – 17	5.2	5	0 – 13	4.0	4
Northern	1 – 5	3 .1+ 1.2 BCN appt	3 + 1	0 – 9	2.3	2
South Eastern	1 – 11	4.5	5	0 – 40	6.7	2
Southern	1 – 19	6.4	6	0 – 33	8.7	6
Western	1 – 9	2.3	2	0 – 51	7.3	4
Total	1 - 19	5	4	0 - 51	6	3

This information was collated through the TCFU Regional Programme Manager following submission from Trust TCFU Project Managers of 50 patients per Trust (total 250) diagnosed with breast cancer 2008/2009 and tracked for 4 years.

There are 1,461 new breast cancer diagnoses each year, with some patients waiting past their clinically indicated time for their first appointment...

Baseline activity data for breast cancer patients was gathered from each Trust for 2010/2011 (12 month period) and analysed to compile the table below.

Trust	New breast cancer diagnoses per year (2011)*	No. of patients attending surgical breast clinics**	Breast patients on surgical waiting list waiting past clinically indicated time (Nov 11)***	No. of review (excl new) patients attending oncology breast clinics**	Breast patients on oncology waiting list waiting past clinically indicated time (Nov11) ***	Additional surgical breast cancer review clinics held (2011)**	Additional oncology breast cancer review clinics held (2011)**
Belfast	414	3,518	163	3,674	300	21	36
Northern	291	1,450	304	2,097	406	78	15
South Eastern	256	1,418	Not quantified	2,250	126	17	0
Southern	252	Not quantified	Not quantified	2,436	0	7	0
Western	248	1,064	96	1,570	163	20	12
Totals	1,461	7,450	563	12,027	995	143	63

* Information obtained via Trust's CaPPs data

** Information obtained via Trust TCFU Project Managers

*** Information obtained via PMSID (November 2012)

The table above demonstrates the baseline information obtained through Trust's CaPPs system on the number of new breast cancer diagnoses each year (i.e. 1,461 across NI). This baseline data also provides detail on breast surgical and oncology appointments, together with detail on waiting lists taken at a point in time (November 2011) and additional clinics performed.

From this, it has been possible to model the number of appointments (surgical and oncology) which would be better utilised over a five year follow-up period. This is based on the assumption that 30% of all newly diagnosed breast cancer patients are moved onto SDA. Results from this modelling exercise (undertaken by NICaN) are shown in the slides which follow.

* Note that the figure of 1,461 new breast cancer diagnoses each year across NI is based on data provided by Trusts from their CaPPs system. This may differ from figures on breast cancer diagnoses from the Northern Ireland Cancer Registry (NICR). The difference between these two sets of data can be explained as the NICR does not include figures for patients with Ductal Carcinoma in Situ (DCIS), and figures from NICR are based on the patient's home postcode rather than the hospital attended.

If 30% of all newly diagnosed breast cancer patients are moved to SDA, this group would otherwise require the equivalent of 4,818 review appointments in any given year...

NICaN’s modelling exercise compared the number of appointments patients would be likely to have in the first five years of follow-up on both the traditional follow-up model and on the SDA pathway. The tables and paragraphs which follow set out the findings from this modelling exercise (figures are based on the baseline audit of Trust data shown on the previous slide).

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.

Current review pattern – Traditional follow-up model	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
Total number of times patient is reviewed over 5 years	3	2	2	2	2	11

Based on CaPPs data (2011), there are 1,461 new breast cancer diagnoses each year in Northern Ireland. If 30% of all new patients are moved to SDA (i.e. 438 patients/year), this group of patients would require the equivalent of 4,818 review appointments in any given year of care if they were to remain on the traditional follow-up model. This is explained in the table below.

Reviews required for 438 patients on traditional follow-up model	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Surgical reviews based on 438 patients	438	438	438	438	438	2,190
Oncology reviews based on 438 patients	876	438	438	438	438	2,628
Total number of reviews required in any given year	1,314	876	876	876	876	4,818*

* Run rate in any given year

If 30% of all newly diagnosed breast cancer patients are moved to SDA with a revised pattern of hospital follow-up, there is potential to better utilise 2,891 surgical & oncology review appointments in any given year...

The table below now shows the proposed pattern of hospital follow-up activity for patients if they were moved to the SDA pathway.

Future review pattern – SDA pathway	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Number of times patient is reviewed by surgery	1	-	-	-	-	1
Number of times patient is reviewed by oncology	1	-	1	-	1	3
Total number of times patient is reviewed over 5 years	2	-	1	-	1	4

Therefore, if 30% of all new patients are moved to the SDA pathway (i.e. 438 patients), this group of patients would require the equivalent of 1,927 review appointments over five years of care via the SDA pathway. This is explained in the table below.

Reviews required for 438 patients on SDA pathway	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Surgical reviews based on 438 patients	438					438
Oncology reviews based on 438 patients	438		438		438	1,314
Rapid access reviews (based on data from Hillingdon’s rapid access audit, it has been shown that 8% of all patients on SDA would require a medical clinic appointment in a given year)						175
Total number of reviews required over 5 years	876		438		438	1,927*

* Run rate in any given year

When the number of appointments is compared amongst the two models of follow-up (traditional and SDA), this suggests that 2,891 appointments could be released/ better utilised each year.

Whilst SDA has the potential to better utilise 2,891 surgical & oncology review appointments in any given year, a further 491 appointments will be required with Breast Care Nurses each year...

However, whilst the SDA pathway offers the possibility of releasing a large number of surgical and oncology review appointments each year, patients moved to the SDA pathway will also require access to other services, such as support from Breast Care Nurses (BCN) (for Holistic Needs Assessments (HNA) and care planning), telephone calls (via the Breast Care Nursing rapid access point) and Health and Wellbeing events. The table below shows the likely extent of this activity for the estimated 438 patients who will be moved to the SDA pathway each year.

Additional review activities for patients on SDA pathway	Appointments
Number of scheduled appointments for patients on SDA to be reviewed by BCN (one HNA and care planning appointment)	438
Of those SDA patients utilising rapid access facility – 3% required a BCN clinic appointment based on findings from Hillingdon audit	53
Total BCN appointments in any given year	491
Total number of telephone calls (via BCN rapid access point) related to SDA patients per year Based on findings from the Hillingdon audit, 29% of all patients on SDA used the rapid access telephone services	508
Number of Health and Wellbeing events proposed related to SDA	18 events

In undertaking this modelling exercise, NICaN has made the following assumptions:

1. Variance in individual cases will affect release of appointments – the modelling exercise has been compiled utilising a conservative approach and these figures only act as a guide to demonstrate potential release. The approach and findings within this modelling exercise were agreed by Trust Cancer Managers through the TCFU Steering Group.
2. Additional clinic time for the consultant is required to undertake the SDA appointment (explaining the programme). This could be at the surgical and/or oncology clinic.
3. BCNs are crucial to the success of the overall programme through the provision of Holistic Needs Assessment and care plans, coupled with education to empower patients within the SDA pathway. This appointment requires additional time to undertake.
4. The Hillingdon Audit (via Prof Jane Maher, 2013) was utilised to provide guidance on rapid access telephone uptake and resultant medical and breast care nurse appointments. Findings from this audit have been used to inform the modelling.
5. Health and Wellbeing events involve a multi-disciplinary approach and need to be embedded into the new pathway.

Findings from the baseline patient survey were broadly similar to those from the English Cancer Patient Experience Survey, with some notable exceptions...

From the 234 postal surveys which were sent to patients across the five HSC Trusts in NI, 115 responses were received (49.1% response rate). The purpose of the survey was to establish a baseline of patient views on the traditional follow-up model from those who were treated for breast cancer in one of the Trusts between 2008 and 2011. It should be noted that findings from the baseline patient survey cannot be considered statistically significant due to the relatively small sample size (234 patients contacted with 115 responses). This survey will be followed up with further surveys as part of this evaluation, and will be supplemented with findings from the NI Cancer Patient Survey in 2013.

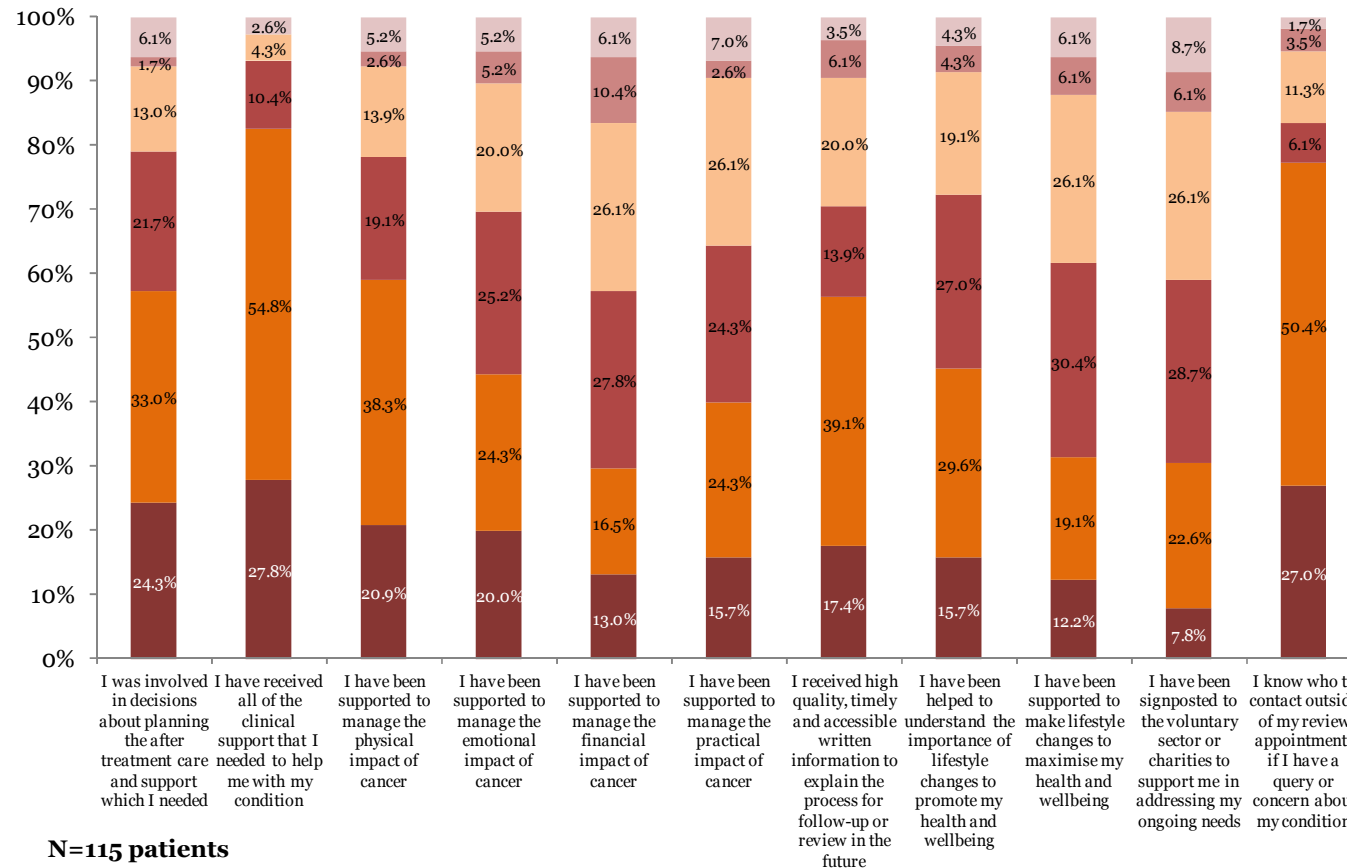
The baseline patient survey reinforced findings from the baseline data which had been gathered by Trusts, in that most patients (65.2%) were having annual reviews with their surgeon and nearly half of patients who responded (49.6%) were having an annual appointment with their oncologist. Within the survey, some questions were kept consistent with the Cancer Patient Experience Survey 2011/12 in England¹ to allow broad comparisons to be made (it should be noted that the survey in NI was on a smaller scale than that in England, with 115 responses received compared to over 70,000 in the English survey). Key comparisons are shown below:

Question	Comparison between NI baseline patient survey and Cancer Patient Experience Survey (England)
At your last outpatient appointment with a doctor (your consultant surgeon or oncologist), did you find the length of time they spent with you too long, too short, or about right?	In NI, 10.4% of patients thought that their appointment was ‘too short’, compared to 5.1% of patients in England.
Did hospital staff give you information about support or self-help groups for people living with or beyond breast cancer?	In NI, 51.3% of patients were given this information, compared to 58.9% in England. 17.4% of NI patients did not receive this information but would have liked it, compared to 13.3% in England.
Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	In NI, 26.1% of patients were given this information, compared to 29.0% in England. 29.6% of NI patients did not receive this information but would have liked it, compared to 26.6% in England.
Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital or following your most recent appointment?	In NI, 67.0% of patients were given information about who to contact, compared to 60.2% in England.
At any point during your treatment and follow-on aftercare, were you offered a written assessment and care plan?	12.2% of patients in NI were offered a written assessment and care plan, compared to 20% in England.
Sometimes people living with or beyond cancer feel they are treated as 'a set of cancer symptoms' rather than as a whole person (an individual). In your NHS care over the last year, did you feel like that?	34.8% of patients in NI indicated that they ‘often’ (3.5%) or ‘sometimes’ (31.3%) feel that they are treated in this way, compared to 20% of patients in England (where 4% indicated ‘often’ and 16% indicated ‘sometimes’)

Most patients received the clinical support they needed, but were less well supported in managing the financial and practical impacts of cancer...

Patients were asked to indicate their views on a range of different statements relating to their cancer care and support in NI. Responses are shown in the chart below, and key findings have been highlighted.

Views on cancer care and support in Northern Ireland



N=115 patients

Strongly agree Agree Neither/Nor Disagree Strongly disagree Don't know/not sure Not stated

- 82.6% of patients strongly agreed/agreed that they received all of the clinical support that they needed
- 59.2% of patients strongly agreed/agreed that they were supported to manage the physical impact of cancer
- 44.3% of patients strongly agreed/agreed that they were supported to manage the emotional impact of cancer
- 29.5% of patients strongly agreed/agreed that they were supported to manage the financial impact of cancer
- 40.0% of patients strongly agreed/agreed that they were supported to manage the practical impact of cancer
- 31.3% of patients strongly agreed/agreed that they were supported to make lifestyle changes to maximise their health and wellbeing

Findings: Outcomes and impact from the breast TCFU programme to date

4

“...thank you for the review... I found it very appropriate for the stage of recovery I’m at.... it is great to know I can just ring and talk to someone or make an appointment as and when for reassurance.”

(Breast cancer patient)

In recent months, the number of patients moving onto Self-Directed Aftercare (SDA) has been increasing across each of the Trusts...

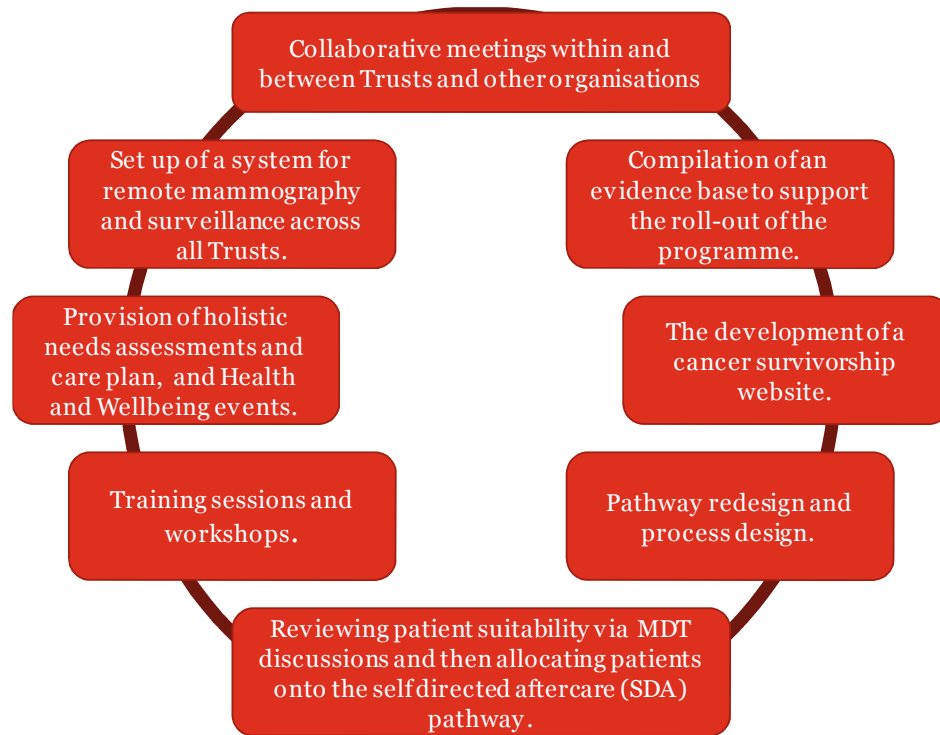
This section of the report sets out early stage outcomes, achieved during 2012 and early 2013. In this time, the programme structures (regionally and within Trusts) were set up, and only more recently have patients been identified and moved onto SDA. As of June 2013, 428 patients had been moved onto SDA. This represents (on average) 35% of all newly diagnosed breast cancer patients who are now being moved to SDA across the five Trusts, demonstrating the increasing rate of progress in this area.

Focus groups with Trust staff also indicated that whilst there are currently a relatively small number of patients moving onto the pathway, progress is being made and the pace and impetus is now increasing. Sometimes monthly totals in each Trust are impacted by patients not being suitable for SDA. Progress being made was also echoed by the wider stakeholders.

“For the breast programme, all Trust have engaged, though some have more patients on the pathway than others”. (Wider stakeholder)

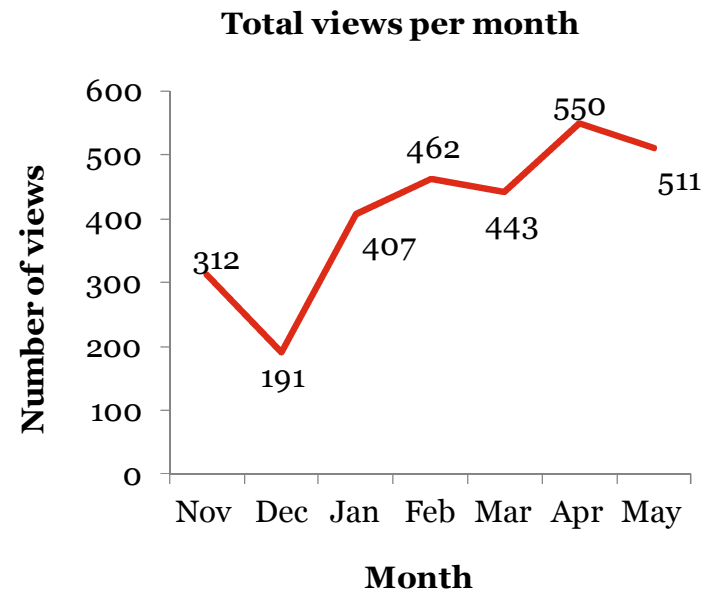
Beyond the increasing number of patients being moved onto SDA, the TCFU programme is demonstrating a range of outcomes and achievements to date...

Beyond the increasing number of patients being moved onto SDA, interviewees and focus group participants cited a number of outputs and outcomes and achievements within the TCFU programme to date:



**The NI Cancer Survivorship website
www.survivorship.cancerni.net**

This website was launched in November 2012 and has seen steadily increasing usage with a total of 2,326 views between Nov 2012 - May 2013. HSCNI views are not included in the figures due to firewall restrictions.



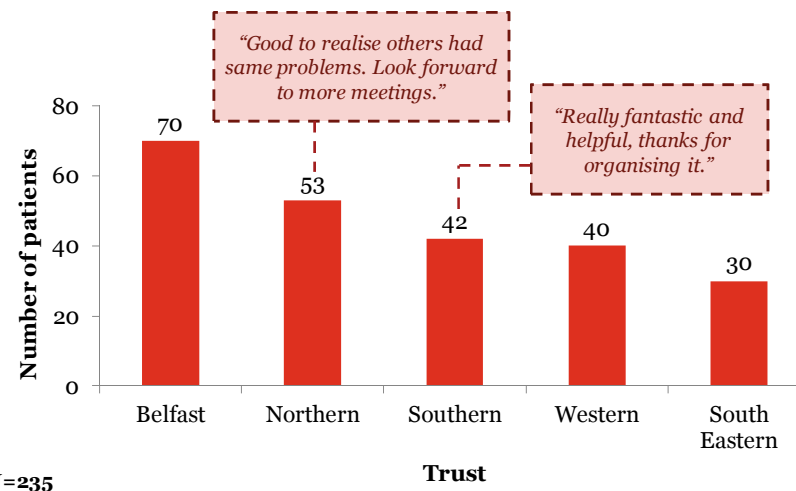
Health and wellbeing events provide education, information and signposting to wider support for cancer survivors, and are being delivered across all Trusts...

A total of 235 breast cancer patients attended cancer health and wellbeing events (across the Belfast, Northern and Southern Trusts), education days (in the Western Trust) and “Moving Forward” programmes (in the South Eastern Trust).

These health and wellbeing events are focused on providing education to cancer survivors through passing on relevant information and signposting to other support services that are available. They are designed to provide brief introductions to a range of services and participants can follow up with these services if relevant to them. The events vary in length (usually between two and three hours), time of day (morning, afternoon, evening) and in content with some being specific to certain cancer types and others being open to people with all types of cancer.

These events are often co-created by a range of health professionals (including consultants) and wider representatives from the statutory and non-statutory sector. Co-creation should bring benefits to patients, particularly in terms of helping them to manage the wider impacts of cancer, which the baseline patient survey showed were not always being met within the traditional service. In some instances these events have been held in the community, thus helping to promote the ‘shift left’ of services, away from traditional service provision in line with the ethos of Transforming Your Care. The community setting is also helpful in making the events easily accessible. A breakdown of attendants by Trust is shown in the chart .

Attendance at Cancer Health and Wellbeing events per Trust



Health and Well-being events - Good practice case study

Some focus group participants indicated that the health and well being events have been successful so far. It was highlighted that at one particular event, a lady who had been through the whole process, told her story to the group. A number of other patients in attendance found this to be extremely helpful.

“My greatest pleasure is my health and well being events. While there is work in it, you come away thinking ‘I have done something right today’. It’s the contact with the patients and the patient experience”. (Wider Stakeholder)

Feedback from these Health and Wellbeing events has been positive, based on data gathered by the Trusts and the NICaN team...

Evaluation forms were distributed at the end of the health and well-being events and feedback themed into four categories:

Support from professionals

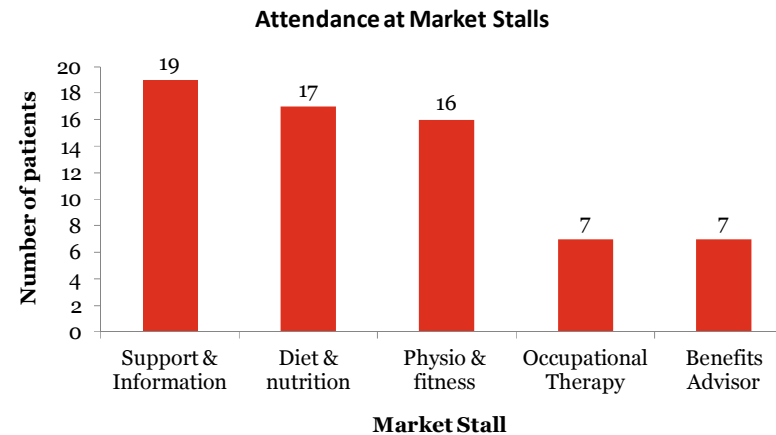
- Information provided by the Breast Care Nurses was found to be very useful and patients found all staff to be well informed.
- Being able to ask questions and taking part in one to one sessions with staff proved useful.

Information on services

- The array of information provided and standard of delivery were found to be of a very high quality, enabling patients to access facilities/ services in the local area which were previously unknown to them.
- Speakers and topics were relevant and informative, and the atmosphere was relaxed. Events were held away from clinical premises to make it less formal.
- A large number of patients felt these events would have been more beneficial to them earlier in their treatment pathway. More advice/support was requested regarding the impact of cancer on family members.

Presentations/ Market Stalls

- Within the events presentations were delivered and market stalls provided further information and advice. A total of 66 patients attended these Market Stalls.



Support from other patients/ carers

- Attendees found it reassuring to meet others who had/ are having the same experience as themselves.
- Hearing other people's stories was reported to be an invaluable experience which helped them feel "normal".

We have considered evidence on the outcomes and impact of the TCFU programme, based on the three aims for this evaluation...

The remainder of this section compares the traditional follow-up model with the TCFU model, in terms of:

- Patient experience/ satisfaction;
- Service integration and co-ordination; and
- Efficiency and resource utilisation.

Evidence has been drawn from views expressed by HSC Trust Staff, wider stakeholders and the Cancer Survivorship Collaborative.

At this stage of programme implementation, and thus in the evaluation, it is too early to provide tangible examples of outcomes and impact from the TCFU. This is because in most instances, patients across Trusts are just starting to be moved on to SDA and thus as their first annual review (if they were to have been still under the traditional model) is not yet due, it is difficult to measure impact. However we have indicated in this report the progress which has been made to date, against each of the three areas to be addressed within this evaluation.

Trust staff and other stakeholders highlighted a number of ways in which the traditional model struggles to deliver high levels of patient experience / satisfaction ...

Trust staff cited issues around receipt of regular complaints from patients regarding:

- Increasing waiting times for review appointments;
- A lack of value being added through review appointments (staff indicated that appointments were often of a very short duration and tended to be with a different clinician at each visit, thus limiting the clinicians ability to go beyond reviewing the patient's history and performing a clinical examination in these timescales); and
- Patients who are anxious about returning for appointments to the place where they were diagnosed.

However Trust staff also highlighted that despite the above, many patients like the reassurance which annual review appointments provide in the absence of other options.

The Cancer Survivorship Collaborative and wider stakeholders reiterated these statements but also indicated that patients were satisfied with the traditional model of follow-up as no other options were available. Some also felt that the number of follow-up appointments were unnecessary.

“Every day you’re getting phone calls saying ‘I was due in February and this is now September’ – we explain that people haven’t been forgotten about and they are on a list but you have to go in order that you were put on the list.”
(HSC Trust staff)

“Patients do hang a lot on these review appointments and they like being told that “everything looks OK.” (Cancer Survivorship Collaborative)

“Appointments can be an inconvenience, waste of time and money and are of questionable value. However for complex patients, sometimes these appointments are completely necessary as they require regular input.”
(Wider stakeholder)

Stakeholders identified multiple benefits which are likely to result in enhanced patient experience / satisfaction from implementation of the TCFU model...

A number of benefits of the new model were identified by Trust staff such as:

- Better educated patients;
- Positive feedback from Health and Wellbeing events, empowering patients to self-manage through the provision of information and by enhancing their confidence, capacity and capability to do so;
- Less travel for patients and less time spent waiting at clinics;
- Reduced anxiety due to the provision of a Holistic Needs Assessment (HNA) and care plan;
- Annual mammogram results being provided directly to the patient and their GP; and
- Direct and rapid access to clinics if the patient has any worries in future.

All of these benefits have already started to be realised for patients on SDA (with the exception of direct and rapid re-access – the extent to which these benefits have been realised will be explored in later waves of this evaluation). However most of these impacts are qualitative and therefore cannot easily be measured in terms of improved quality or cost-effectiveness at this stage.

Additionally Cancer Survivorship Collaborative stakeholders indicated the importance of promoting more widely the range of third sector organisations (both those who participate in the Collaborative and beyond) and making these services more widely available across NI.

“We had one lady who came in with her checklist score as an 8 and she felt at the end of the [Holistic Needs Assessment and Care Plan] event she could score herself as a one or a two, so just having that chat with [the breast care nurse] to go through all her concerns, she had completely changed how she rated herself.” (HSC Trust staff)

“People should get information on a range of services, know what to look out for, who to ring and get a responsive service. Overall people should feel empowered.” (Wider stakeholder)

“There needs to be more links to established charities to get the support and information to help people self manage.” (Cancer Survivorship Collaborative)

Whilst existing services have achieved integration over time, demand pressures have led to fragmentation...

On the whole, Trust staff indicated that the traditional system was satisfactory in terms of integration and co-ordination, as it had been in place for many years. However others did highlight fragmentation and issues with surgical and oncology review appointments running together, when these are ideally meant to be spaced at six monthly intervals.

Wider stakeholders highlighted the lack of co-ordination between all sectors in the traditional system. This related to clinicians being unaware of the services provided by Third Sector organisations and therefore not providing patients with the information they need.

Cancer Survivorship Collaborative members also indicated the need for co-ordination and consistency of services provided across all Trusts. They also indicated that the referral route needs to be more integrated with clinicians being aware of the services provided by the Community and Voluntary sector.

“Previously, I saw someone one week, who had been in oncology the week before – that’s not the plan. There’s meant to be six months apart. It wasn’t wasteful, but it’s not how it’s meant to work. There was a little inconsistency.” (HSC Trust staff)

“Clinicians don’t know what support services there are available and where to refer patients.” (Wider stakeholder)

“There needs to be consistent services available no matter where you are in Northern Ireland and this isn’t the case currently.” (Cancer Survivorship Collaborative)

The TCFU model is likely to improve co-ordination of services, so patients see the right person in the right place at the right time...

Overall Trust staff were positive about the potential impact of the programme with regard to service integration and co-ordination, particularly in terms of pointing patients to the right person, in the right place at the right time, in line with the strategic objectives of Transforming Your Care.

Trusts have highlighted that the impact of the TCFU model is being observed through moving patients onto the SDA pathway and those patients attending Health and Wellbeing events. Some concerns were also raised, such as

- The timing of moving patients onto SDA which was sometimes when treatment was still taking place (there was little consensus between different professionals and across the Trusts as to when this might be);
- A fear of 'losing' patients who are not regularly followed up; and
- The need for further communication about the programme to patients and service users (including potential service users in the future).

Cancer Survivorship Collaborative members and wider stakeholders highlighted there is a need for the Community and Voluntary sector to be closely involved in service delivery with Trusts, to provide the services to empower patients to self manage their condition. They also felt that if TCFU works as intended it will free up resources for those who need it.

“The new pathway will point people in a direction that they need to be pointed and so it’ll take less appointments to get to the person you need to see. If I’m sick, you want to be seen by the right person at the right time in the right place. I think this programme could deliver this.” (HSC Trust staff)

“It will improve communication between hospitals and GPs, by providing GPs with information on how to re-refer patients, provide guidance on a wide range of services and information on toxicities.” (Wider stakeholder)

“There is a role for the community and voluntary sector organisations to be working with statutory services so that people aren’t left feeling high and dry, and that they’ve got support that they need.” (Cancer Survivorship Collaborative)

Efficiency and resource utilisation in the traditional system is characterised by issues around appointment duplication and delays...

The main issues raised by all stakeholders in terms of efficiency and resource utilisation were around:

- Duplication of appointments (particularly between surgery and oncology);
- Delays in review appointments; and
- Mammograms having to be repeated due to sub-optimal scheduling of various clinic appointments.

Cancer Survivorship Collaborative stakeholders indicated that the number of cancer patients and survivors are rising and placing increasing demands on the system.

Review appointments were seen to be “routine” and often do not add value therefore seen by some stakeholders to be wasteful.

“The traditional model doesn’t meet commissioner’s, manager’s, doctor’s or patient’s needs – it is a production line and no-one gets a quality service. It is wasteful and there is duplication of appointments.”
(Wider stakeholder)

“There are capacity issues and they’re [HSC system] struggling to cope with new diagnoses and the targets for it. We receive calls from patients who are anxious because they haven’t received an appointment for their review.” (Cancer Survivorship Collaborative)

“Ideally patients should see the oncologist and surgeon at 6 month intervals but often this didn’t happen as appointments were running late.” (HSC Trust staff)

There is potential for the TCFU programme to enhance efficiency and resource utilisation by freeing up clinic space and providing longer slots for patients who need them...

A number of positive aspects associated with implementation of the TCFU programme were recognised by all stakeholders, such as:

- Clinic space being released for new patients or more complex patients;
- Being able to provide longer appointment slots; and
- The potential for reducing the need for extra ad-hoc clinics.

To date, Trusts have not yet realised the impact of additional clinic space or clinics being released or longer slots. This is because in most instances, patients across Trusts are just starting to be moved on to SDA and thus as their first annual review (if they were still under the traditional model) is not due yet, impact cannot be measured. It is anticipated that for these impacts to be realised, full implementation will be required.

However some concerns, such as a fear over the number of phone calls which might be received from concerned patients who are on SDA, along with the time needed to undertake a thorough Holistic Needs Assessment (HNA) and complete a care plan were cited as potential issues. At present, Trusts varied in terms of time spent on HNA, (between 45 minutes – 1.5 hours) however, the learning from across the UK has shown that with training and experience the variation in time required is reduced.

“You will be able to see more new patients and the more complex patients. One in four people might get cancer in the future, so the more we can see that we need to see, then it would bring benefits.” (HSC Trust staff)

“If wasteful follow-up appointments can be reduced, other patients might be able to get a longer slot with their consultant.” (Wider stakeholder)

“There won’t be nearly as many review appointments as there are at present, so it will definitely ease the system, whether or not it will improve quality of life and patient satisfaction remains to be seen.” (Cancer Survivorship Collaborative)

In the majority of Trusts, a review of patients on surgical and oncology waiting lists has resulted in less duplication...

The table below shows the number of patients appearing on both oncology and surgical review clinic waiting lists across Trusts in NI.

The Belfast, Northern, Southern and Western Trusts have all shown a decrease in the number of duplicate appointments (between 32-68) since commencing the TCFU programme. The average reduction in duplicate appointments within these four Trusts is 55, and in total across these four Trusts has reduced by 220 patients. The avoidance of duplication between surgical and oncology appointments shows the potential for clinicians, with growing confidence in the programme, to streamline resources.

Whilst duplication has increased within the South Eastern Trust, this is explained as during the months between November 2012 and February 2013, SDA implementation was on hold due to issues such as sick leave amongst the team. These issues have since been resolved and SDA implementation recommenced in March 2013.

Going forward duplication figures will be produced on a quarterly basis.

Trust	November 2012	April 2013	Difference
Belfast	771	712	↓59
Northern	561	493	↓68
South Eastern	353	413	↑60
Southern	501	450	↓61
Western	375	343	↓32

Findings: Reflections on the process and learning from the TCFU programme to date

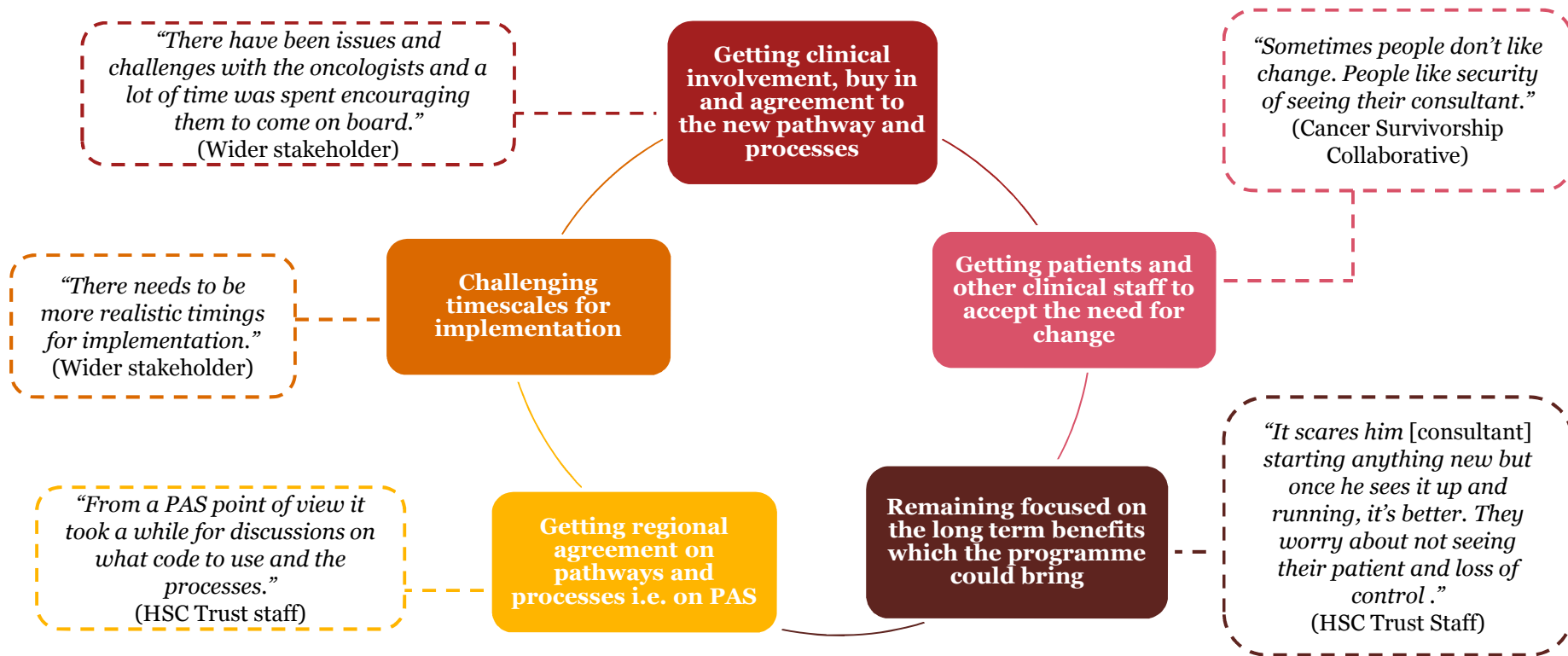
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“[The TCFU programme is] a good idea and makes sense. There are always difficulties, there always are no matter what work you do. In the long term it makes sense”.

(HSC Trust staff)

Given the complexity of this large scale system change there are challenges associated with implementation, some of which have been overcome. However, timescales remain a challenge...

Those who took part in the evaluation were asked for their views on the main challenges of implementing the programme so far. These are shown in the diagram below. Each of these barriers have largely been overcome through ongoing communication at a variety of levels (this has proved particularly important in keeping everyone on board), supported by the agreement of criteria for patients who will be put onto the SDA pathway and the development of regional PAS guidance. Clinical involvement has largely now been secured for the breast programme through ongoing communication and engagement, although it remains a challenge for Trusts to ensure that all clinicians are on board with all aspects of the changes. Issues around the timescales for implementation still remain of concern for Trusts.



A number of critical success factors have helped to drive the programme forward, particularly TCFU Project Managers, a regional focus and good communication with staff and patients...

Stakeholders highlighted a number of success factors which they thought were critical for getting the programme to the current point. These are shown in the diagram below.

HSC Trust staff in particular were keen to highlight the role which the TCFU Project Managers have played in driving the programme forward. Linked to ongoing pressures around timescales mentioned on the previous slide, staff indicated that ongoing support from Project Managers would be critical to future success.

Similarly clinical involvement has been critical and stakeholders across all groups felt that buy-in and visibility of clinical leaders could be further enhanced in the future.

Many Trust staff reflected on the key role played by Breast Care Nurses (BCNs), particularly in conducting HNA and care planning, and Health and Wellbeing events. Information provided by NICaN suggests that there are currently 17 whole time equivalent BCN posts across the five HSC Trusts in NI, although this falls short of national standards and other areas of the UK, based on data from a national benchmarking exercise in 2011¹. This benchmarking exercise is currently being repeated nationally, and thus the role of BCNs will be considered in more detail in subsequent waves of this evaluation.

Wider stakeholders

- Having the programme strongly endorsed by commissioners and not being optional

“The programme is now in the commissioning plan for NI and has endorsement at senior level”.

Trust staff

- Further ongoing resources to assist in implementation and roll-out, particularly from administration staff, breast care nurses and TCFU Project Managers
- Staff across the pathway all working together to optimise processes
- Communication about the programme, coupled with word-of-mouth support and positive feedback from patients
- Further funding (to support the resources described above)
- Extra time at MDT meetings to discuss patients suitable for the SDA pathway – both new patients and existing review patients

“It will all boil down to staffing levels and will depend on the sort of numbers [of patients] coming through...it all comes down to resources and funding.”

Cancer Survivorship Collaborative

- Buy in from third sector organisations who are willing to help in order to enhance services
- Communicating positive patient feedback on use of Third Sector services to health professionals to help promote these further
- Changing the mindset of GPs to use charities/ organisations as service providers alongside statutory services

Across the system, stakeholders have learnt about the importance of communication, team working, and strong people management to support implementation...

Stakeholders who took part in the evaluation highlighted the following as key learning from the programme to date:

<p>The need to have clear action plans and deadlines, both at regional levels and within each Trust, which are actively managed</p>	<p>Involvement of a wide range of staff from an early stage (e.g. not just staff in cancer services, but also those in elective surgical care)</p>	<p>The need for good communication between clinical and administrative staff, to promote clarity as to which patients are going on the SDA pathway</p>	<p>The need for having people with the right skills to lead change going forward</p>
<p><i>“Probably do action plans which have clear deadlines of when you expect things to be done, regionally and within the Trust. There needs to be clear lines of communication through the Trust and keep up to date on where the region is”.</i></p> <p>(HSC Trust staff)</p>	<p><i>“You need to have a shared vision and understanding from the outset, and secure the right type of buy in”.</i></p> <p>(Wider stakeholder)</p>	<p><i>“It’s about the consultants giving clear and concise information to secretaries about what they want done”.</i></p> <p><i>“We need to know whether patients are going to go on SDA or not”.</i></p> <p>(HSC Trust staff)</p>	<p><i>“One of the challenges has been to get the right level of oversight... centrally and within Trusts. All individuals must understand the services as well as have good project management skills”.</i></p> <p>(Wider stakeholder)</p>

Support provided was viewed as helpful, and further opportunities for sharing learning and good practice would be valued...

Across all HSC Trusts, stakeholders were happy with the level of support received, both from within their own Trusts and from NICaN and Macmillan, and did not request any further support. Many Trusts recognised that at this point, they just needed to 'plough ahead' with implementation.

NICaN were seen as the key drivers in bringing people on board and securing regional agreement, with Macmillan playing a key role in providing support and funding to get the project underway.

HSC Trust staff provided particularly positive feedback on the workshops run by NICaN. There was a strong desire for similar events in future to encourage sharing of good practice between Trusts and learning from each other.

“The Project Manager is a very important role. With any project, the day work still continues so you need someone to step out from their day job and back fill that person, to allow this project to have a life of its own while the work is being done.” (HSC Trust staff)

“[NICaN] were at the information day and spoke, she was informative. [Another Trust] were there and showed how they do it – just a few comparisons and so you could talk to peers elsewhere. In 12 months time it would be good to have a follow-up or feedback, as it will start to affect different groups of people as the other sites get rolled out”. (HSC Trust staff)

Most GPs we spoke to indicated that awareness and understanding of the TCFU programme is relatively low...

A sample of 50 GPs across the five HSC Trusts (ten from each Trust) were contacted on the basis that these GPs have had contact with at least one patient who has used breast cancer services in the years 2008 to 2011. In addition to this, all GPs across the primary care system in NI have been provided with information on the TCFU programme through a number of channels, such as: presentations to Local Commissioning Groups (LCGs), uploading programme information on the GP intranet, dissemination of newsletters and individual GP letters for patients on the SDA pathway.

From this, one interview was arranged (highlighting difficulties in engaging GPs in the evaluation). The sample was widened to include interviews with five Macmillan GP facilitators. Whilst this is likely to have skewed the sample given that the Macmillan GP facilitators will have a greater awareness of the TCFU programme than other GPs, these interviews highlighted some useful points around GP awareness and views about the programme. For example, most of the Macmillan GP facilitators believed that their colleagues would be unaware or know very little about the programme. GPs highlighted the following benefits and issues with the traditional model and perceived challenges associated with the TCFU programme:

Benefits of the traditional model

- Mechanisms for follow-up are clearly defined and well established, so GPs know when their patients will be reviewed by the secondary care team.
- GPs know how the system works and are familiar with the various processes.
- There is a clear route back into the system if patients experience a problem.
- GPs are reassured that patients are being followed up by specialists in secondary care.

Issues with the traditional model

- Three of the six GPs interviewed indicated that the current system is not timely, as patients are often being reviewed later than expected.
- Patients become anxious when they are not sent review appointments on time.
- Letters are often delayed in reaching GPs following reviews.
- Does not assist in dealing with issues in between follow-up appointments.
- Consultant time could be better utilised by focusing on more complex cases.
- Review clinics at the hospital tend to be overbooked and it can be difficult for GPs to get patients back into the clinic quickly if required.

Comments on the TCFU Programme

Given that most GPs were not fully aware of the TCFU programme, and had not seen it in operation for any of their patients at this point in time, most highlighted areas where they would appreciate further clarity, such as:

- Clarity over who has responsibility for the patient, i.e. Primary or secondary care.
- Guidance over who to speak to in each Trust should a patient need to be re-referred.
- Perception that there may be fewer resources in clinics if there are to be fewer follow-up appointments, and therefore concerns that there may not be enough staff to deal with volume of patients.

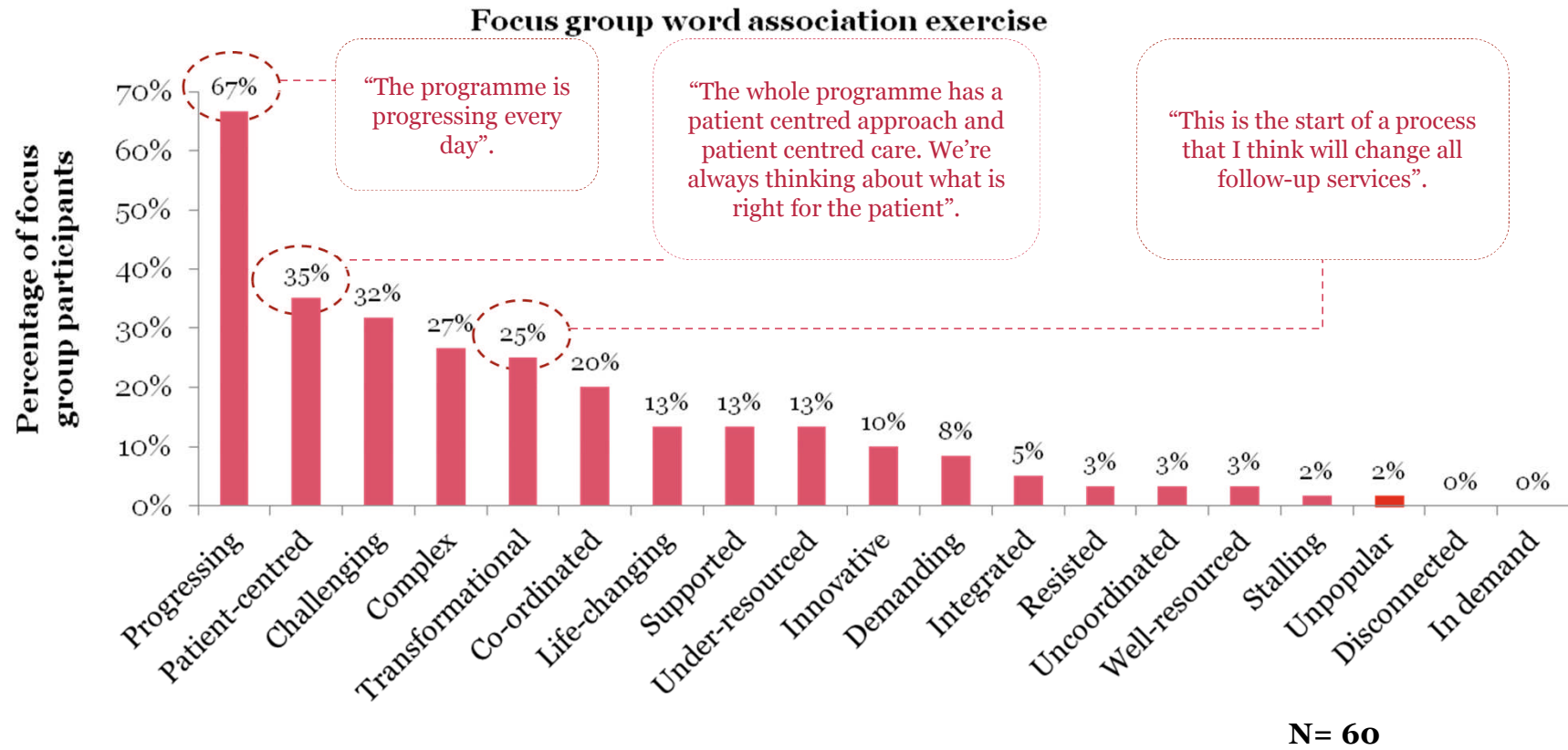
“I didn’t have to take responsibility for them [review patients] and sort out mammograms. I’m only called on if there are any issues getting appointments.”

“People have tried to do their best but there is very little resource...as all the clinicians time has been spent on routine follow-up appointments.”

“I don’t think a lot of GP’s who don’t have a specific interest in cancer and palliative care would know much about this [programme]. I don’t think there has been enough information filtered down to general practice.”

HSC Trust staff most commonly described the TCFU programme as “progressing”, “patient-centred” and “challenging”...

In order to summarise views about the TCFU programme to date, HSC Trust staff who took part in focus groups were asked to choose three words from a list of 20 which they felt best describes the progress of the TCFU programme in their Trust at that time. Findings are shown in the chart below:



Areas for consideration

6

Stakeholders identified seven areas for consideration, relating to communication, patient and public expectations and project timescales...

Stakeholders highlighted seven areas for consideration, as shown in the table below and overleaf:

Area	Key observations...	Moving forward...
Communication	<ul style="list-style-type: none"> ✓ Awareness of the programme is generally high amongst staff dealing with Breast cancer patients in secondary care. ✓ Whilst information has already been sent to GPs, our discussions highlighted that there is still limited knowledge and understanding of the programme amongst primary care professionals. 	<ol style="list-style-type: none"> 1. Ongoing communication is required across the healthcare system to highlight the rationale and benefits of the programme for all cancer areas. This will help in achieving clinical buy-in and support for the programme as it rolls out to other cancer sites and potentially to other disease areas. 2. Further communications to GPs should enhance their understanding and support for the programme.
Patient , service user and public expectations	<ul style="list-style-type: none"> ✓ In most instances, only patients who have moved onto SDA are aware of the TCFU programme, and often are made aware through discussions with their clinician during their treatment pathway. ✓ These discussions are relatively time consuming, given that the new model of care and process for reviews differs from what patients and the public might expect from secondary care. 	<ol style="list-style-type: none"> 3. The aims and objectives of the programme should be communicated to current patients and those affected i.e. wider family, carers and the general public. This would help in setting expectations around follow-up care in the future, and would support clinicians in ‘selling’ the programme and concepts to patients and the public.

“Sewing the seed early on is important with the patient, informing them about the new pathway and that the traditional model isn’t being used with them, as well as letting them know it is for their benefit and that it is a better review system.” (HSC Trust staff)

Stakeholders identified seven areas for consideration, relating to project timescales and ongoing support for implementation...

Area	Key observations...	Moving forward...
Project timescales	<ul style="list-style-type: none"> ✓ Most stakeholders agreed that the early stages of setting up the project and implementation had taken longer than originally envisaged. ✓ Whilst they agreed that all of the work that has now been completed was necessary and worthwhile, this has meant that the remaining time available for implementation of the breast programme (and also the prostate programme) has been reduced. 	<p>4. An extension to the timescales would help to promote full, high quality and sustainable implementation of the programme in these two cancer sites, and could help in rolling the programme out to other sites.</p>
Ongoing support for implementation	<ul style="list-style-type: none"> ✓ Stakeholders have generally been complimentary about the role of Project Managers in driving the project forward, and thus their input across Trusts will be required to complete implementation for existing cancer sites and to role this out more widely. ✓ The workload associated with the TCFU programme for Breast Care Nursing and administrative staff has been manageable so far, however as the number of patients on SDA increase, this may change. 	<p>5. Ongoing staff resources - particularly the TCFU Project Managers - are likely to be required to support implementation.</p> <p>6. There will also be a need to continually monitor the workload of administrative staff and Breast Care Nursing staff, to see if assumptions around the number of patients who re-enter the system from SDA are proving accurate, and whether workload is manageable.</p>

“There is still so much work to be done; I don’t see how we can get it finished. We need [project manager] to still be in post. In other cancer areas, these might be able to go a lot quicker, and obviously a lot of issues have been resolved in the implementation of the breast programme but I think the fact that there is still so much work to be done, I don’t think it is feasible.” (HSC Trust staff)

Stakeholders identified seven areas for consideration, relating to clinical leadership, Holistic Needs Assessments & care plans and Health & Wellbeing events...

Area	Key observations...	Moving forward...
Clinical leadership	<ul style="list-style-type: none"> ✓ Stakeholders recognised that it had been difficult to secure clinical leadership across all Trusts and specialties for the breast programme. 	<p>7. In order to smooth the process of full implementation of the breast programme, and potentially enhance the roll-out of the programme to other cancer sites, clinical leaders should be more visible in each cancer site area in each Trust, and at Steering Group level. Clinical leaders should also be supported to progress the programme.</p>
Holistic Needs Assessments and care plans	<ul style="list-style-type: none"> ✓ Stakeholders across each Trust highlighted variation in current practice for undertaking Holistic Needs Assessments (HNA) and care plans, particularly in terms of the time taken to perform these assessments. 	<p>8. It would be worthwhile to examine what is working well or less well in each Trust with regards to HNA and care planning in order to identify good practice, and roll out an agreed approach on a regional basis. This would include agreeing timings for undertaking HNAs and care planning with patients on their cancer pathway.</p>
Health & Wellbeing events	<ul style="list-style-type: none"> ✓ There has been positive feedback on Health and Wellbeing events so far. ✓ Joint design and delivery across professionals in secondary care and alongside voluntary sector organisations has helped build and maintain awareness and build confidence amongst patients and consultants. ✓ These events demonstrate clear learning for Transforming Your Care in terms of supporting the shift left. 	<p>9. Events should be continued and extended where possible. There may be benefits in extending these to wider groups of patients to promote self-management, such as those who are still within the traditional model, or have been recently discharged after five or more years follow-up.</p> <p>10. These events should be formally co-created (on an on-going basis) across the key stakeholder groups including primary, secondary and voluntary sector organisations. There were suggestions that these events need to be an integral part of the care pathway and should be based in the community to promote self-management outside of the acute setting.</p>

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