



# EVALUATION OF THE STOBHILL TRANSFORMING CARE AFTER TREATMENT PROJECT

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Phase 1 – Final Report

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## Acknowledgements



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We would also like to thank NHS Greater Glasgow and Clyde (NHSGGC) staff who participated in focus groups or interviews and everyone who participated in interviews including the project team.

Finally and most importantly we would like to thank the patients who participated in the project and contributed to the patient questionnaires openly and honestly. In addition we thank the members of the Stobhill Patient Experience panel who gave up their free time to support the design and delivery of the project.

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YOUR  
CANCER CARE

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## Glossary of terms

Abbreviation	Definition
BCC	Breast Cancer Care
BHNA	Breast Holistic Needs Assessment
CNS	Clinical Nurse Specialist
ENU	Edinburgh Napier University
HSC	Health and Social Care
HNA	Holistic Needs Assessment
ICJ	Improving Your Cancer Journey
MCN	Managed Clinical Network
MDT	Multi Disciplinary Team
RCAG	Regional Cancer Advisory Group

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## Executive Summary...

The findings from this pilot focusing on supported self management and annual mammograms are significant. There is evidence of an improved patient experience of follow-up and a 49% reduction in consultant appointments. This reduction demonstrates an image-led model can offer substantial opportunities for improved resource utilisation.

The pilot outcomes show an image-led model of follow-up can support the aims of the Scottish Government Quality Strategy to realise the 2020 Vision. The Quality Strategy aims to deliver the highest quality healthcare to the people of Scotland to ensure that the NHS, Local Authorities and the Third Sector work together, and with patients, carers and the public, towards a shared goal of world-leading healthcare.

The 2020 Vision also states “We will have a healthcare system where we have integrated health and social care, a focus on prevention, anticipation and supported self management.”

The ‘average post TCAT patient’ shows an increase in ability to manage their own condition, feels more supported since treatment, and reports a decrease in the feeling they have been passed around from person to person. Evidence from the pilot shows that the new Breast Holistic Needs Assessment empowers the patient and makes them feel more involved in their follow-up care.

This pilot is the first of its kind within Glasgow and is a significant breakthrough. The evidence from the pilot could be used to inform the review of breast follow-up guidance currently underway by the Breast Cancer Managed Clinical Network (MCN), and as a roadmap to inform the redesign of follow-up services across the region.

### Quality Ambitions

Based on the Institute of Medicine’s six dimensions of Quality and informed by what the people of Scotland told us they want from their healthcare system (Caring, Compassionate, Communication, Collaboration, Clean environment, Continuity of care and Clinical excellence), three Quality Ambitions were developed:

**Safe** - There will be no avoidable injury or harm to people from healthcare.

**Person-Centred** - Mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values and which demonstrates compassion, continuity, clear communication and shared decision-making

**Effective** - The most appropriate treatments, interventions, support and services will be provided at the right time to everyone who will benefit, and wasteful or harmful variation will be eradicated

## Executive Summary Continued...

The image-led model also supports improved health and social care integration with new links being formed between the acute setting and local support organisations. The project team have worked collaboratively with Breast Cancer Care (BCC) and the Breast Cancer Nurse Specialists (CNS) at Stobhill are now signposting all patients to the Moving Forward Course. The overall aim of this course is “to enhance the provision of existing local support services on a range of topics affecting people living with breast cancer after diagnosis and during recovery”.

The Moving Forward Course has seen a 33% increase in demand and a new 4 weekly course has been added in August 2016 to meet this additional demand.

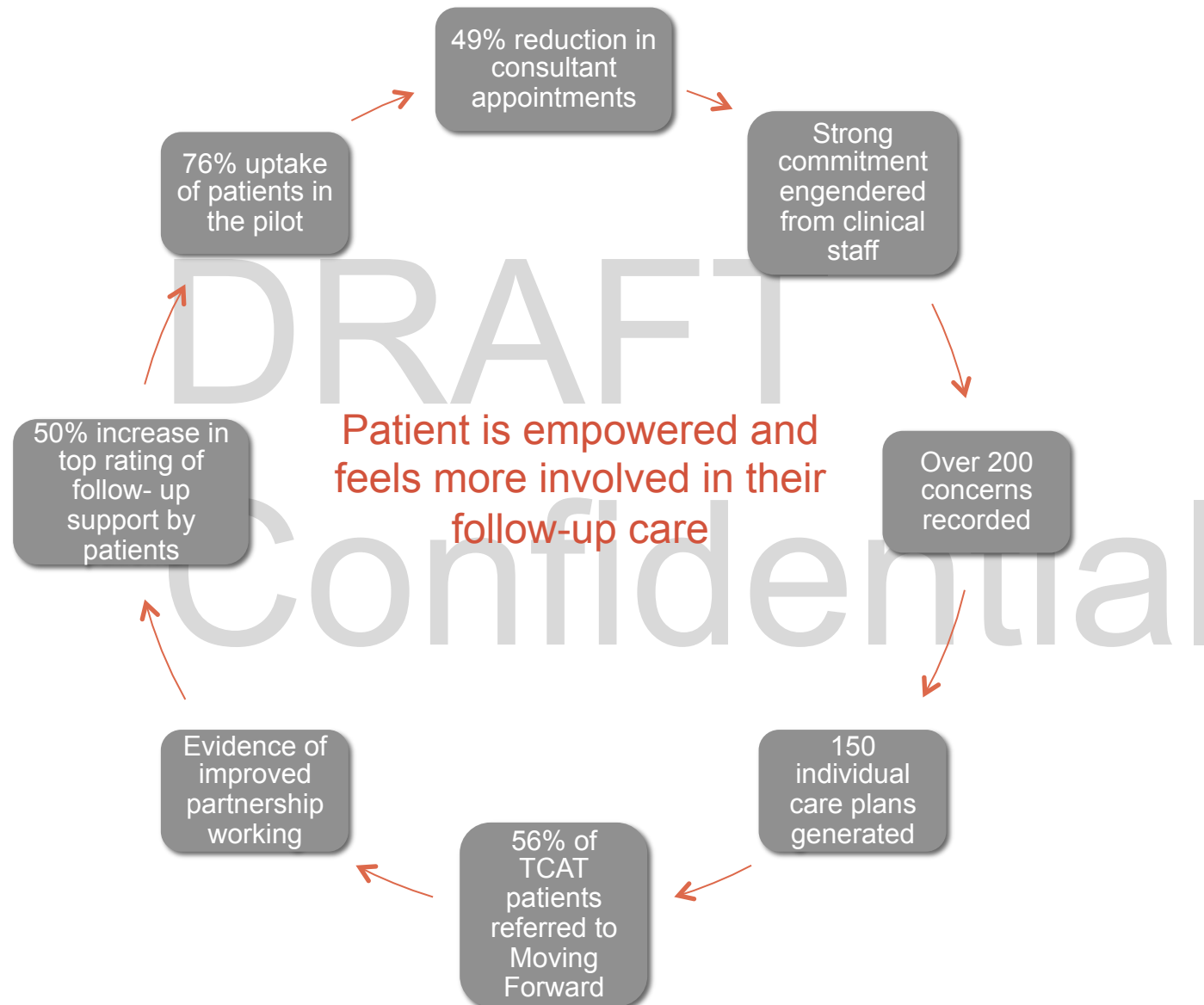
Improving Your Cancer Journey is a Macmillan funded support service that is able to offer a HNA and ongoing support to cancer patients within the Glasgow City area. ICJ now run a Thursday session onsite at Stobhill and there has been 100% increase in referrals from the Stobhill Breast Team.

Another key achievement has been the high uptake on the pilot of 76% indicating that image-led follow-up is acceptable to patients. This is supported by additional evidence from the evaluation that shows TCAT patients feel significantly more empowered and involved in decisions about their follow-up care.

The pilot has also engendered a cultural change. Through collaborative working with clinical staff and patients on it’s design and delivery, and the emerging improvement in patient experience, a strong staff commitment to the new model of follow-up has developed.

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## Key achievements of the Stobhill TCAT Pilot...



# INTRODUCTION

*“The TCAT programme is needed as the current models of follow-up are unsustainable given the needs of the population and demands on clinics”*

*Northern Ireland TCAT Trust Staff*

*“Simply doing more of the same will not deliver the outcome improvements cancer survivors expect, nor will it be affordable to the NHS.”*

*National Cancer Survivorship Initiative*

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## *There is a clear rationale for enhancing the effectiveness of the follow-up system for people with breast cancer...*

The Stobhill Breast Service was awarded one years Phase 1 TCAT funding by Macmillan Cancer Support in the first quarter of 2015 to pilot a new holistic model of follow-up focusing on supported self-management and annual mammograms. This is a change to current follow-up where patients are followed-up for 10 years via an annual consultant appointment.

The Stobhill Project is the first of its kind within Glasgow and aims to:

- Pilot an image-model of care which focuses on supported self-management and annual imaging;
- Improve support to patients transitioning from acute to community, reducing unnecessary hospital contact and enhancing quality of life;
- Improve communication across all sectors and ensuring patients have an appropriate person-centred follow-up plan;
- Signpost or refer patients to local support organisations specific to their needs.

This project is part of a five year Scotland wide TCAT programme which is a partnership between the Scottish Government, Macmillan Cancer Support, NHS Scotland, Local Authorities and Third Sector organisations. The project focus is on the care and support of people after treatment for cancer. The overarching aims of TCAT are to:

- Enable people affected by cancer to play a more active role in managing their own care;
- Provide services that are more tailored to the needs and preferences of people affected by cancer;
- Give people affected by cancer more support in dealing with the physical, emotional and financial consequences of cancer treatment;
- Improve integration between the different service providers and provide more care locally.

*“The experience and quality of life that people with cancer have through and beyond diagnosis and treatment is equally as important as clinical effectiveness and safety. It is therefore essential that we strive to deliver cancer care in ways to ensure that people receive the support they need to live as long and healthy a life as possible”*  
Beating Cancer: Ambition and Action SG  
Cancer Plan 2016

## *The Stobhill TCAT programme aims to improve patient experience, reduce unnecessary hospital appointments and build community links...*

Current follow-up for breast cancer patients is not as effective as it could be<sup>1</sup>. Most recurrence is detected outside follow-up and many appointments add little value to either patients or their families. Follow-up is currently treated as an acute illness which is now not the case for many patients.

Follow-up appointments often do not meet patients needs and a lack of capacity in the system for review appointments has been a cause for concern leading to interference in returning to everyday life<sup>2</sup>. Evidence shows that many of these breast cancer survivors have unmet needs particularly at the end of treatment. Many are struggling with the consequences of treatment that could be avoided or managed<sup>3,4,5</sup>, yet often contribute in repeat visits to hospital clinics.

Changing the way we support cancer survivors is both an outcome priority to address unmet need and a financial priority to meet the increasing demand and subsequent unfunded cost pressure: simply doing more of the same will not deliver the outcomes improvement cancer survivors expect, nor will it be affordable to the NHS<sup>6</sup>.

The Stobhill TCAT pilot is also aligned to a number of organisational and national priorities – the Scottish Government Health and Wellbeing Strategy<sup>7</sup> and review of cancer follow-up by the Breast Cancer MCN<sup>8</sup>. As well as The Scottish Government Quality Strategy and the Patient Experience Quality Performance Indicators<sup>9</sup>.

- **Around 32,000 people in Scotland were diagnosed with cancer in 2013, an increase of around 12% since 2003 and is expected to reach 40,000 diagnoses by 2023-27<sup>10</sup>.**
- **It is predicted that there will be approximately 24,431 cases of breast cancer diagnosed in Scotland during 2016-20 and around half of these people will reside and receive treatment in the West of Scotland.**
- **Stobhill Breast Service currently has approx. 260 new diagnoses every year with over 2000 patients currently in follow-up.**
- **Referral statistics to the Stobhill Breast Service comparing 2014/15 and 2015/16 show an increase of 371 patients with 2832 patients referred in total in 2015/16, with clinic slots showing a capacity difference of -1160.**
- **It is in this context that the Stobhill Breast Service TCAT pilot was carried out.**

*“After my hospital treatment finished I felt abandoned and didn’t know where to turn”*  
TCAT Patient Event Attendee

## *The aim of this evaluation is to provide an assessment of the likely impact of and learning's from the new model of follow-up for patients with breast cancer...*

In early 2011 a critical review of existing literature related to follow-up was undertaken. This compared different types of follow-up care including clinic or telephone consultation, clinician versus specialist nurse and radiographer/ specialist nurse consultation (Velindre model: NHS Wales)<sup>11</sup>.

Although current practice was similar to recommendations by National Institute for Health and Clinical Excellence (NICE) and American Society of Clinical Oncologists (ASCO), most reviews concluded that there is no evidence from randomised trials to support any particular follow up sequence or protocol.

A coordinated approach by surgeons, oncologists, radiologists, radiographers and specialist nurses is recommended and the ongoing management of breast cancer patients and the above information was utilised to develop a regional consensus guideline, which defined an optimal future model of care.

The purpose of this evaluation is to provide a robust assessment on the impact of and learning from of a new image-led model of follow-up at Stobhill on: 1) patient experience and satisfaction, 2) resource utilisation and 3) service integration.

The report considers the likely impact of changes on the pathway and also what has been learnt from designing, planning and implementing this new model of follow-up.

The specific objectives and key questions which the evaluation aims to address are shown in the diagram on the following page.

The pilot project encompassed 38 TCAT Mammogram Clinics between 28<sup>th</sup> October 2015 and 13<sup>th</sup> July 2016. During the pilot, 191 patients were invited to to attend TCAT image-led clinics, with 150 consenting to participate (76% uptake).

*This evaluation aims to address a number of key questions on the process, learning, outcomes and impact of the Stobhill pilot...*

### Key Questions

#### Outcome/impact:

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

### Key Questions

#### Objectives:

- Provide data that helps to evidence whether the new models help achieve better outcomes for people with cancer and better resource utilisation
- Draw out evidence and lessons learned on what works and doesn't work, for whom why and in what circumstances – to help inform design and delivery of future services
- Work collaboratively with the project team on the pilot site, and be flexible in adapting the approach and methodology of the requirements if the scope/timing of the project change

### Key Questions

#### Processes/learning:

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

# APPROACH

*“The development of this project has been an important first step in supporting patients and clinical staff to move away from the traditional medicalised model of follow-up care to a more holistic person-centred model. Improvements in capturing patients concerns has led to strong links to third sector support for patients that are now available on site in conjunction with clinics”*  
Consultant Surgeon Stobhill Breast Service

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# Stobhill TCAT Project Plan

Macmillan project plan

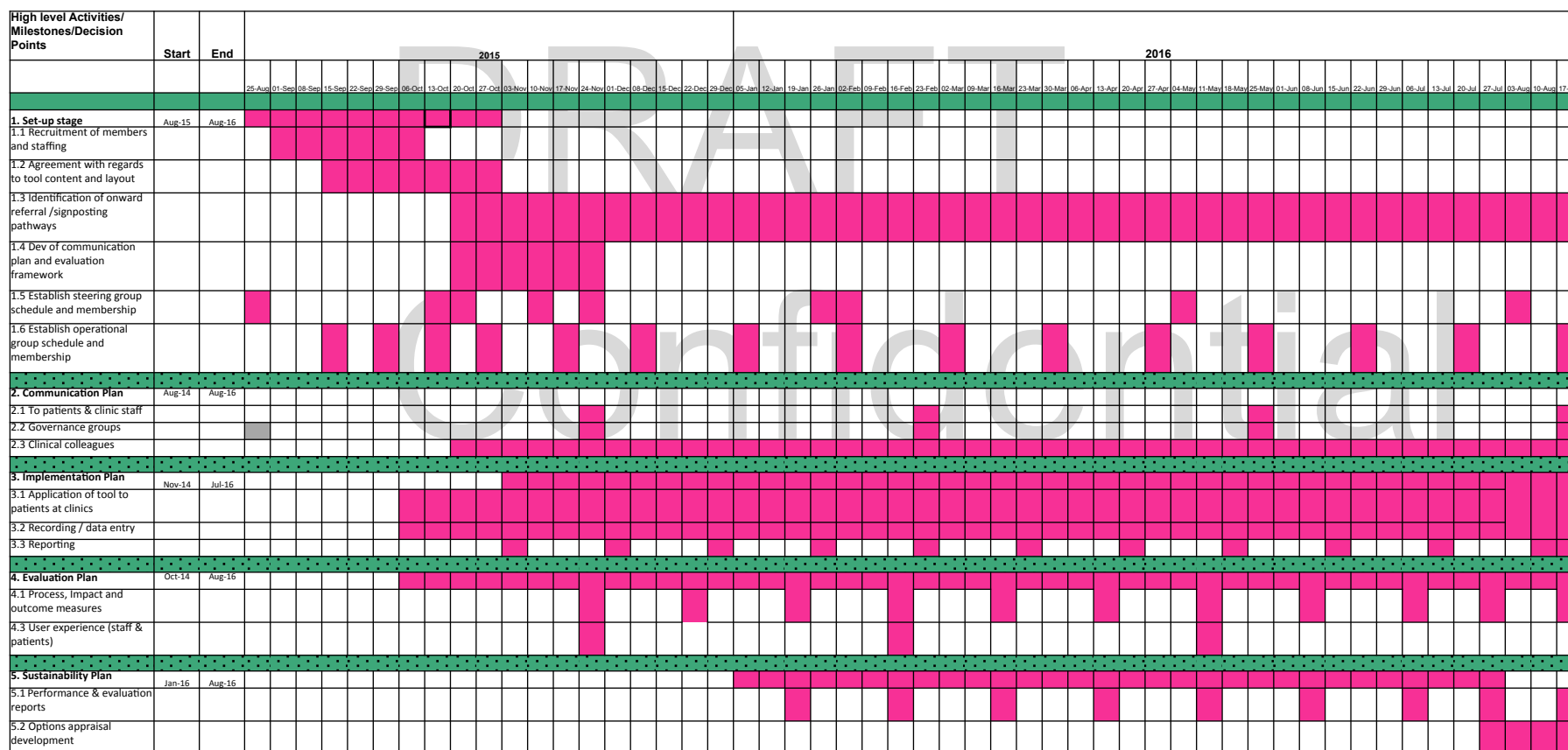
Phase: Planning

Date: 29.9.15

Key	Activity	Milestone	◇	Decision Point	◇
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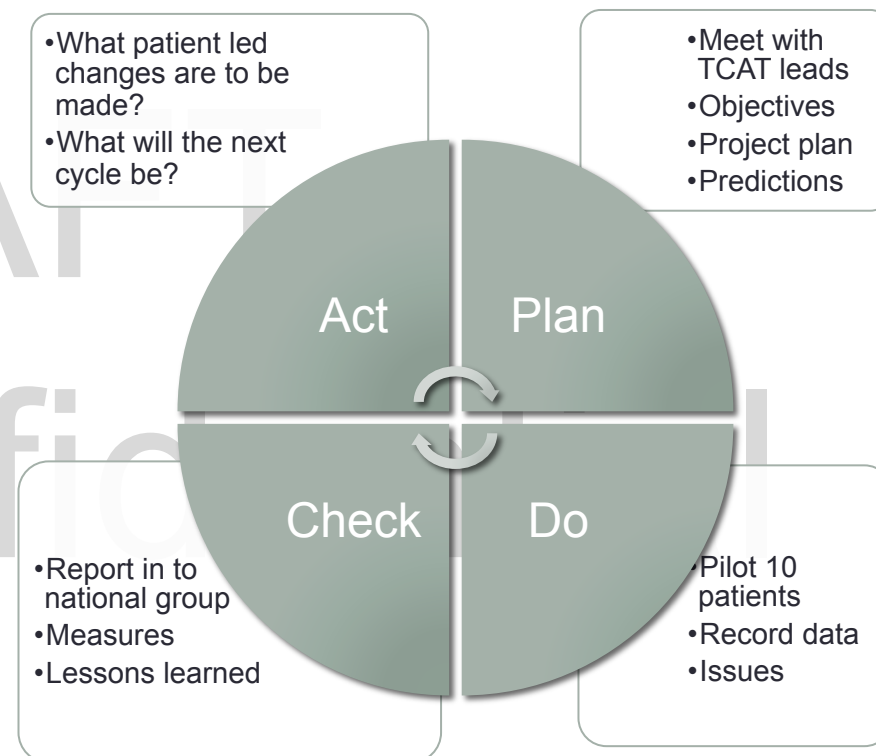
NB: To extend the Gantt chart simply copy any column and paste

Project name: TCAT NE Glasgow Breast Cancer Pilot  
 Project sponsor: Cancer Services Steering Group  
 Project manager: Anna Morton



## Method

- A project manager was appointed to work with the clinical team and implement the project and a multi-agency steering group was set up
- 191 suitable patients were invited to attend a TCAT Mammogram Clinic between 28<sup>th</sup> Oct 2015 and 13<sup>th</sup> July 2016 and sent a BHNA to find out what support needs they may require
- Cancer Nurse Specialists (CNS) reviewed the BHNA and triaged into: 1) no further action 2) CNS phone call 3) Clinic appointment or 4) signposting/referring to other services in the community
- TCAT staff built new links with third sector and local government organisations and developed more effective referral pathways
- A Patient Experience Group was set up to oversee the design and delivery of the project
- Plan, Do, Study, Act (PDSA) service improvement approach was adopted
- Other tools employed included logic modeling (see Appendix 1) and process mapping



## *Multi-faceted methodological approach was taken to the project...*

Short Life Operational Group	A total of 8 operational group meetings took place with Stobhill clinical staff. The meetings took place every 2 weeks initially and then once a month. Members of the Multidisciplinary Team (MDT): Radiographers, CNSs, Surgeons, Administrative Staff and the TCAT Project Manager attended.
Baseline Pre TCAT Patient Survey	Edinburgh Napier University (ENU) pre TCAT patient survey was given to patients who attended a Patient Experience Event and the Moving Forward Course based at Stobhill. In total 34 patients responded to the pre TCAT questionnaire.
Post TCAT Questionnaire	ENU post TCAT questionnaire was sent out to 112 patients from the November 2015-May 2016 patient sample. A total of 46 patients returned the questionnaire giving a response rate of 43%.
Patient Experience Group	A Patient Experience Group was set up to support the design and delivery of the project. Patients were recruited from a Patient Experience Event on 1 <sup>st</sup> March 2016 organised by the team. 15 patients attended this event and 5 patients went on to join to project group which met in April and June 2016.
Interviews with the project team and patients	A number of interviews were held with the project team and patients and these were analysed by the project manager.
Analysis and reporting	All interviews were written up using a thematic approach and reported on within this document



## *Stakeholder engagement via the steering group, operational group and focus groups with staff and patients...*

A Multidisciplinary Steering Group was set up to provide on-going advice and guidance to the project team on the approach, new pathways, governance, HNA tools, accessibility, evaluating tools and reports.

There were 4 quarterly meetings during the lifespan of the pilot in August, November 2015 and February, May 2016.

The project manager reported to the group and provided regular project updates to key stakeholders via email, phone and written highlight reports. The project manager also attended Learn and Share Events and liaised with other TCAT Project Managers to share learning's from the design and development of the project.

The project manager organised a TCAT Patient Event on March 1<sup>st</sup> 2016 hosted by BCC which 15 patients attended. A Patient Experience Group was set up to oversee the design and delivery of the project and 2 meetings took place.

Governance and quality was maintained by NHSGGC Quality Team.

Profession	Number
Project Sponsor GGC Director	1
Consultant Surgeons	2
Cancer Nurse Specialists	4
Clinical Service Manager	1
Radiographers	6
Patient Representatives	6
TCAT Project Manager	1
Macmillan National, & Associate Regional Leads	3
WoSCAN Network Service Manager	1
Senior Health Improvement Staff	2
Nurse Manager	1
MCN Manager	1
East Dunbartonshire CHP Lead and PM	2
Third Sector Directors and staff	4
ENU Researcher	1
<b>Total</b>	<b>36</b>

## *We have made a number of assumptions in compiling this report and have faced some limitations in undertaking the evaluation at this stage...*

In undertaking the evaluation of Phase 1 of the Stobhill Project we have endeavored 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**

The Project Manager with support of ENU has used skills in qualitative data gathering, probing and critical analysis to elicit open and honest views from stakeholders. From this we have assumed that views from these stakeholders are representative of others in their organisation, profession and/or sector.

### **Limitations**

There were delays to the start of the project caused by recruitment issues and staff changes as well as wider changes within the Board. As such when the project manager started working 15 hours a week in mid-August 2015 there was a requirement to quickly move the project to implementation in order to maintain momentum and the first 8 weeks of the project were used to develop the BHNA and pathway to ensure they were safe and effective and met current quality standards in terms of accessibility. This and the project timeline meant that it was not possible to compare the same patient experience with the same cohort (longitudinal) going from diagnoses to first year of follow-up.

The project timeline of 1 year meant there was limited time to prepare patients for the new model and provide them with information on any changes to follow-up. Patients were sent a letter 2 weeks before their original follow-up appointment asking them to attend a TCAT Clinic instead and were offered the opportunity to discuss any concerns with a CNS. Patients also received a text message confirmation of their original appointment 24 hours before which caused some confusion and unfortunately the project team were unable to stop this going out. All of this may have impacted upon the patients experience of the TCAT pilot and image-led follow-up.

Due to timescales this evaluation will compare pre and post TCAT responses from a patient sample between 28<sup>th</sup> October 2015 and 25<sup>th</sup> May 2016. 147 patients were invited to take part during this time and 112 patients accepted.

Again due to project timescales it was not possible to do a before and after comparison of traditional follow-up and the new model of care with the same patient cohort. As such the baseline questionnaire was given out to patients on the Moving Forward Course and at the Patient Experience Event and the post TCAT questionnaire was sent out to all patients who attended the TCAT clinic between 28<sup>th</sup> October 2015 and end May 2016.

*We have made a number of assumptions in compiling this report and have faced some limitations in undertaking the evaluation at this stage continued...*

A postal approach to the post TCAT survey was undertaken and again due to timescales it was not possible to send out reminders to the patients. Even with this limitation 42 out of 112 patients returned the questionnaire. This is a good response rate in terms of a postal survey.

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# BREAST FOLLOW-UP PATIENT LED MODEL

*"It was good to have the opportunity to write down my concerns so they won't be forgotten. I felt that they were recognised by the health team discussed and action taken. It showed an understanding of what you were going through."*

Stobhill TCAT Patient

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*Following Assessment and risk stratification by the multi-disciplinary team it is anticipated that 70% of patients with breast cancer could transition over to the new model of care...*

The current model of follow-up at Stobhill involves patients being seen at a one stop clinic for a consultant visit and mammogram annually for 10 years post treatment. Patients make their first annual follow-up appointment when they are diagnosed.

The output of a review of follow-up practice recommended an optimal future model of follow-up care and the guideline was ratified by the Regional Cancer Advisory Group (RCAG) and formally issued to the 4 WoS NHS Board for implementation in August 2012. Following assessment, discussion and risk stratification by the multi-disciplinary team it was anticipated that 70% of patients with breast cancer could transition over to an image-led model of care which acknowledges that not all women are suitable for a common pathway for post-treatment follow-up and individual patient circumstances can sometimes require a different approach. The table below shows a comparison between the exclusion criteria ratified by RCAG and those used by the Stobhill pilot :

Original bid	Stobhill TCAT Pilot
<ul style="list-style-type: none"> <li>• Chemotherapy / Herceptin</li> <li>• Endocrine Therapy</li> <li>• High-risk Gene Positive</li> <li>• Metastatic Disease</li> <li>• Bilateral Mastectomy</li> <li>• Clinical Trials</li> </ul>	<ul style="list-style-type: none"> <li>• Bilateral Mastectomy</li> <li>• Primary Endocrine Therapy</li> <li>• Metastatic Disease</li> <li>• DCIS – could be included in future</li> </ul>

The Stobhill project found that more patients than originally anticipated were suitable for image-led follow-up (i.e. 73% as opposed to the above estimate of 70%). Based on an average of 260 new diagnoses in a year the Stobhill pilot invited 191 patients to take part in 9 months.

**Recommendation: Patients were selected manually by CNSs and it is recommended that should the image-led model be adopted patients are risk stratified at the MDT when diagnosed/reviewed and put on either image-led or clinic-led follow-up.**

## *191 patients were invited to attend the image-led clinic and 150 agreed, giving an uptake of 76%...*

- 191 TCAT patients were invited to take part between October 2015 to July 2016 via a letter (see Appendix 2) sent out 2 weeks before their original clinic appointment inviting them to attend a TCAT Mammogram Clinic. This included the BHNA to record physical, emotional, financial and other concerns.
- Once the letters were sent out patient details and mammogram appointment slots were passed to the consultant who booked their appointment on the system.
- Patients filled out the BHNA at home and brought it to their mammogram appointment.
- Cancer Nurse Specialists (CNS) reviewed the BHNA and triaged into: 1) no further action, 2) CNS Phone Call, 3) Clinic appointment or 4) signposting/referring to other services.
- All 112 patients from the sample received an up to 20 minute phone call from the CNS and during this phone call patients were given the result of their mammogram, concerns discussed and appropriate referral and signposting information passed on.
- All TCAT patients received a tailored care plan (Appendix 4) generated as a result of this process and this was scanned on to TrakCare to form part of the patient record.
- Next years mammogram appointment was booked.

### **Learning:**

Pilot TCAT administration processes for sending out letters and booking appointments are quite clunky and time consuming, relying on paper based systems and verbal double checking between administrative and clinic staff to ensure that letters have been sent out and mammogram appointments booked. There is therefore a high margin for human error.

### **Recommendations:**

During Phase 3 an IT System should be developed to support image-led follow-up. This would involve a scoping exercise to look at whether the new pathway could be supported TrakCare or would require a new image-led database system.

## *Stobhill TCAT Radiographer experience...*

The Radiographers from the Operational Group set up a Wednesday afternoon TCAT Clinic with 7 fifteen minute slots running from 1.30-3pm.

Following the commencement of the TCAT questionnaire Radiographers taking part in the project have made the following observations and changes to practice:

- Changes to the way appointments are run to support TCAT patients (i.e. TCAT slots take approx. 15-20 mins as opposed to the normal 5-7 minute appointments.) 7 TCAT appointment slots are available for one mammography room to accommodate the clinic running in the other room.
- Patients can sometimes present as anxious and do have a lot of varying questions and concerns which would be normally be resolved at clinic prior to attending for mammogram.
- Questions normally relate to physical symptoms (scar tissue, pain at scar, radiotherapy site, arm stiffness, lymphoedema). Psychologically some patients are unable to look at the mastectomy/WLE site and feel unable to examine themselves. Others would like advice on breast examination post surgery. There are also concerns/questions about side effects of medication and the duration of the medication.

- Patients did not feel the current breast examination booklets were relevant as they did not contain information regarding post surgery breasts.
- Also of concern is how long before they receive the results of their mammogram, and what will happen if there is an abnormality.
- Radiographers are advising patients that CNS will contact them with results and if there are any abnormalities they will be brought back to a one stop clinic.

*"I thought the staff at the mammogram clinic were very supportive and straight to the point when explaining symptoms"*

*"Reassurance from the mammogram clinic that everything would be ok and know that any concerns that could not be answered that day would be passed via the questionnaire and someone would get back"*

*TCAT Patients*

## *A total of 38 Wednesday afternoon TCAT Clinics were held between October 28<sup>th</sup> 2015 and July 13<sup>th</sup> 2016...*

- On the whole, all first year patients follow-up seem to have an expectation that they will receive results on the same day as their mammogram (regardless of TCAT) since this is what happened when they attended the one stop clinic and were diagnosed the year before.
  - Occasionally the Radiographer has had to contact a CNS to come to department to speak to concerned/ anxious patients.
  - All patients are told if they have any concerns at any time during the year until their next follow up they should contact the CNS.
  - Majority of patients gave positive feedback on the questionnaire and the opportunity it presents to record their concerns. Some were not happy to complete the questionnaire without assistance from the Radiographer or CNS.
  - Most patients were happy with a telephone call from the CNS rather than attend a clinic appointment to discuss their concerns.
  - CNS collects questionnaires from Radiographers on a Thursday after the MDT and the Radiographers pass on any additional comments/observations at this time.
  - Radiographers felt that preparing the patients in advance of the new model of follow-up would help to alleviate some of the patient's anxiety at the mammogram appointment and speed up the appointment time.
- Return patients from year 2 onwards have expressed the opinion they would be happy with a mammogram only and only see a clinician if they have any concerns regarding their treatment.

These findings demonstrate that image-led follow up is acceptable to patients. Patients did not show a strong preference to see a consultant unless required and most were happy with a follow up phone call from a CNS.

### **Recommendations:**

1. **Review of radiographer resource in Phase 3 due increased appointment slots**
2. **Streamlining of process for communicating the results of the mammogram**
3. **Preparing patients at diagnosis for image-led follow-up**
4. **Review of self checking breast examination booklet**



## *150 individual care plans were generated as a result of the BHNA and follow-up CNS phone call...*

### **Patient demographics and clinical characteristics**

The approximate number of patients diagnosed annually at Stobhill is 260 and rising. The Stobhill project selected 191 suitable patients to take part in 12 months, giving a total suitable for the trial of 73%.

Of the evaluation sample 148 patients were invited to attend between Oct 28<sup>th</sup> 2015 and end of May 2016 of that number 112 patients agreed to attend, giving an uptake during that period of 76%.

Due to the nature of the project all of the patients were female, diagnosed with breast cancer.

The age of the patients was spread throughout the age ranges, with 78.6% between the ages of 50-79.

Patients were either in 1st or 2<sup>nd</sup> year with majority of patients 76.8% (76) being in first year of follow-up and 23.2% (26) in second year of follow-up.

Economic data was missing/not known in 56 patients, of the remaining 56 patients, only 28 patients (50%) were employed.

Current living situation was missing/ not known for 54 cases, out of the remaining 58 patients 72.4% were living with a spouse/ partner.

47%(27) of patients were fully active and able to carry out all pre disease performance without restriction, whereas 37%(21) were restricted in ability and 16%(9) were unable to carry out any work activities.

*The Breast Holistic Needs Assessment Questionnaire aims to improve follow-up by focusing more on health and well-being, and not just on physical symptoms and illness...*

The BHNA (Appendix 3) was developed by a multidisciplinary team prior to the project start date to underpin image-led follow-up. The tool was reviewed and approved for use by the research team at ENU. The questionnaire allows patients to record their breast specific physical concerns and also any wider concerns that they may have.

The BHNA is sent out to patients 2 weeks before their mammogram appointments and they can fill it out at home and bring it with them to the appointment to give to the radiographer.

Prior to the BHNA tool there has been no formal way of recording patients wider concerns.

**Learning: The current BHNA tool opens the door to a conversation about patients wider concerns but is more weighted towards physical concerns in it's current form.**

As well supporting the new model of follow-up to ensure that the new process is safe and effective in terms of identifying physical symptoms, patients are also invited to record their wider concerns and provide feedback on the BHNA.

The majority of patients on the pilot responded well to the opportunity to record their concerns and the CNSs welcomed the opportunity to have a structured conversation with patients based around the BHNA.

	Patients
Agreed to fill out BHNA	98% (147)
Found the BHNA easy to read	98% (147)
Found it helpful to record concerns	80% (120)

## *80% (120) of TCAT patients recorded that it was helpful to write down their concerns...*

The BHNA gives patients the opportunity to record both physical and wider concerns and the majority of patients responded well to the opportunity to record their concerns.

Findings below demonstrate that the majority of patients recorded physical concerns and this may be down to the structure of the BHNA which, as it also serves to underpin image-led follow-up, is weighted towards physical symptoms.

There is a single open ended question at the end to prompt other concerns which if repeated may benefit from more explicit routine enquiry of common concerns e.g. financial, social emotional or relationship problems. However the questionnaire works well as basis for a structured conversation with the CNS and it was often via this conversation that patients wider concerns such as side effects of medication or family issues were picked up upon. Both patients and CNSs reported that they benefitted from having this structured conversation.

**Recommendation: Phase 3 would include the introduction of the Macmillan Recovery Package HNA and Treatment Summaries at appropriate stages of the patient journey to prompt patients to record wider concerns. The BHNA should be review and amended for use with patients in 2+ year of follow-up.**

Concerns	% of sample group assessed	Number of people
Physical	80%	120
Practical	8.9%	13
Employment	3%	6
Family	5%	7.5
Emotional	16%	24

*12% of patients in first year of follow-up and 19.2% in second year were referred to Improving Your Cancer Journey showing a 60% increase in second year referrals...*

The aim of the new image-led model is to promote self management from the start of the patient journey and to build new links with local authority and 3<sup>rd</sup> sector support organisations who can support patients wider emotional, financial, family and rehabilitation concerns. All of these concerns can impact on patient recovery post treatment and lead to repeat hospital visits.

The BHNA captures the initial concerns and it is during the follow-up phone call with the CNS that these concerns are discussed in more detail and appropriate signposting given or referrals made to appropriate services.

During the Stobhill pilot new referral pathways were built with Breast Cancer Care and Improving Your Cancer Journey and patients were also sign posted to over 20 additional support organisations.

The local authority referral data analysed by ENU from the patient sample is outlined in the table below. The data indicates an increase in onward referrals to local authority (in this case ICJ) between first and second year patients of over 60% (12.2% compared to 19.2% respectively). The reasons for this difference are beyond the scope of this pilot however this suggests that patients in second year of follow-up appear to be more accepting of external help or may have more need for external support. There are insufficient patient numbers to make firm conclusions at this time. Numbers were small as ICJ only came on site at Stobhill in May 2016, month 8 of the pilot.

	Referred		Not referred	
Follow up	Number	% of Cohort	Number	% of Cohort
1 <sup>st</sup> Year	10	12.2%	72	87.8%
2 <sup>nd</sup> Year	5	19.2%	21	80.8%

## *57% (47) of first year and 42% (10) of second year patients were referred to a support organisation...*

Data were missing for 5 patients, for the remaining 107 patients the table below shows support organisation referral information. There were 15% more referrals for year 1 follow-up cohort (57% compared to 40% for year 2.) These referrals were either to BCC or to an NHS Cancer Specific Service. A total of 33% (28) patients were formally referred to the BCC Moving Forward Course. All patient were offered the opportunity to be referred to Moving Forward during the BHNA follow up phone call with the CNS.

The figures below show that although a high number of the patients did take up the opportunity to be formally referred; 43.4% of first year patients and 58.3% of second year patients did not wish or need for a formal referral to be made. In some of these cases the CNSs sent out information packs to the patients so that they could contact the organisations at a later date should they wish. The aim of this model is to develop a more flexible pathway were patients can receive information at a suitable point on their individual journey.

	Referred		Not referred	
Follow up	Number	% of Cohort	Number	% of Cohort
1 <sup>st</sup> Year	47	56.6%	36	43.4%
2 <sup>nd</sup> Year	10	41.7%	14	58.3%

*A total of 33% (28) of TCAT patients in first year of follow-up were formally referred to BCC's Moving Forward Course. ....*

The formal TCAT onward referral destinations are outlined below. NHS specialist cancer services and cancer specific third sector organisation/charity (majority BCC) are the most common.

Referred to	1 year follow-up	2 year follow-up
NHS Cancer Service	15	3
GP	6	1
NHS General	4	1
Other Local Authority	3	1
Specialist/ Benefits	0	0
Vocational Support	0	0
TCAT Events	0	0
Cancer Specific 3 <sup>rd</sup> Sector	28	7
Other 3 <sup>rd</sup> Sector	6	0

## 41% (46) of 112 TCAT patients returned post TCAT patient feedback questionnaire...

Questionnaire	Service	Support Services
✓ <i>"it was good to have the opportunity to raise concerns"</i>	<i>"Very helpful and informative"</i>	<ul style="list-style-type: none"> <li>• Macmillan Cancer Support</li> <li>• Macmillan Move More</li> <li>• Breast Cancer Care</li> <li>• Beatson</li> <li>• Maggies</li> <li>• Lymphodema Clinic</li> <li>• CNSs</li> <li>• Family</li> </ul>
✓ <i>"I thought it was a chance to raise concerns"</i>	<i>"I thought the staff at the mammogram clinic were very supportive and straight to the point explaining symptoms"</i>	
✓ <i>"Felt all the questions I had were answered"</i>	<i>"My concerns were recognised by the health team, discussed and action taken"</i>	
✓ <i>"It was good to write down my concerns so they wouldn't be forgotten"</i>	<i>"Getting things explained to you in person"</i>	
✓ <i>"In recording your concerns the team might pick up on things"</i>	<i>"Good advice and very nice people to talk to"</i>	
✓ <i>"The chance to voice concerns"</i>	<i>"The friendly, smiling, supportive staff and the efficiency of the service"</i>	
✓ <i>"Being able to record the excellent care I received"</i>		
✓ <i>"The fact that I can state my concerns and help is available"</i>		

## *50% increase in top score when TCAT patients rate the support they have received post treatment...*

Post TCAT patients were asked to rate the support they had received since their treatment with “support” including any advice or information given, and being referred to or signposted to people or organisations that could help you. The table on the following page outlines a 50% increase in patients giving the highest score of 10.

The TCAT project team held a Patient Experience Event at BCC offices on the 1<sup>st</sup> March 2016. There was only capacity for 15 patients who were recruited by BCC and a waiting list was created due to high demand. The patients, who came from across the Glasgow region, were introduced to the aims of TCAT and asked to describe their current experience of follow-up.

Comments opposite from the event are from across Glasgow and are illustrative of views of treatment as usual across GGC.

In the pre TCAT Questionnaires just 5.9% (2/34) responses gave a high scored of 10 in terms of being confident in knowing how to manage their condition themselves post treatment with “managing” meaning understanding ways to cope and knowing where to seek help if needed. By contrast 37% (17/46) gave the highest scoring of 10 post TCAT.

### *Baseline Patient Experience Feedback -*

Comments below are from across Glasgow and are illustrative of views of treatment as usual across GGC.

*“Dreadful it is not joined up. You’re isolated. You get so much support when you’re under treatment and very little after. The Moving forward course was excellent.”*

*“GPs bear the brunt of our problems and may not know the answer or have time to help.”*

*“I found out about Moving Forward through a newspaper not a healthcare professional.”*

*“I finished last session of chemo then felt abandoned”*



*Post TCAT Patients score all areas of their follow-up experience more highly...*

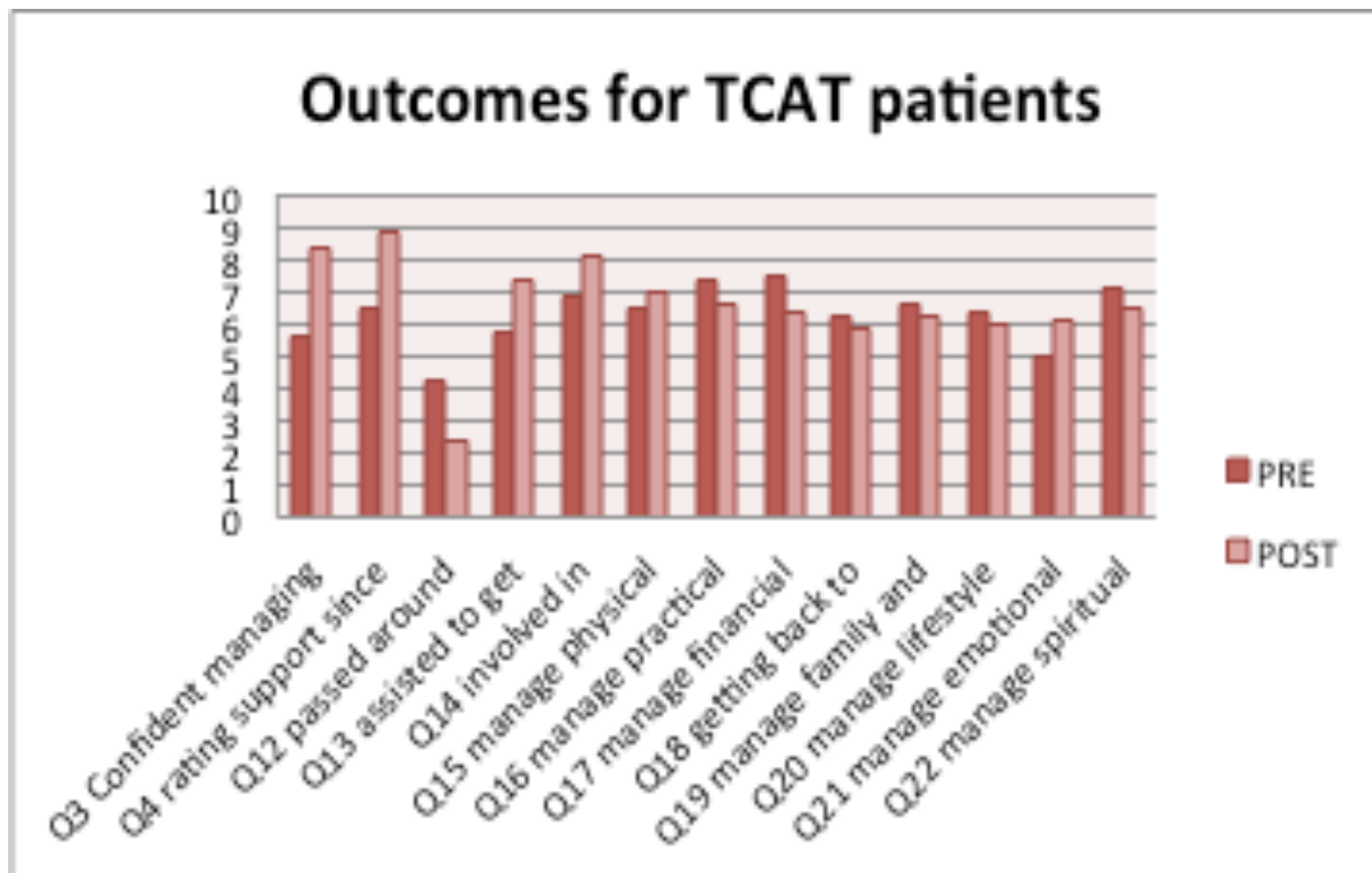
Core data questions	Top score of 10 Pre TCAT (34 patients)	Top score of 10 Post TCAT (46 patients)
How confident were you that you could manage your condition by yourself?	5.9%(2)	36.96%(17)
How would you rate the support you have received since your treatment?	15.2% (5)	58.70%(27)
I was assisted to get services and help, and to put everything together	9.4% (3)	38.10% (16)
I have been involved in decisions about my care	27.3% (9)	34.78% (16)
To manage my physical condition	14.7% (5)	23.81% (10)

## *Pre and Post TCAT Questionnaire comparison...*

	Needs were met completely – pre TCAT	Needs were met completely – post TCAT
Managing the side effects of treatment	23.5% (8)	65.91% (21)
Knowing where to seek help if you needed it?	32.4% (11)	64.58% (31)
Understanding who to ask for help if you need it?	30.3% (10)	73.91% (34)
Awareness of support available to family/carers	18.2% (6)	47.83% (22)
Knowing about other support services you could use	20.6% (7)	45.65% (21)
Awareness of support for family/carers	18.2% (6)	47.83% (22)

## The 'average TCAT participant'...

Changes in pre-post responses to quantitative TCAT questions are outlined in the figure below. By comparing the average score across both forms we hope to understand to what extent the 'average participant' has an improved patient experience. As explained in the limitations section we were unable to compare responses from the same cohort and one recommendation would be a Phase 3 longitudinal study.



## *The 'average post TCAT participant'...*

- **The 'average post TCAT patient' shows an increase in ability to manage their own condition, feels more supported since treatment and reports a decrease in the feeling they have been passed around from person to person. They also feel more involved in decisions about their own care.**
- **This would appear to demonstrate that the BHNA achieved its core function to empower and involve the patient in the coordination of their cancer journey.**
- Although the 'average post TCAT patient' appears to feel more empowered, involved and supported in key decisions in their on-going care the TCAT questionnaire comparison does not indicate any improvement in ability to manage physical, financial or lifestyle concerns. These are complex matters which are unlikely to be readily resolved through the BHNA.
- Although these findings could be down to the inability of the BHNA to record specific concerns and as such a review of the BHNA and the introduction of the Macmillan Recovery Package HNA are recommended as per p22.

## *49% of TCAT patients did not need a consultant appointment...*

Of the 150 patients who attended the TCAT Mammogram Clinic 49% (74) did not need to have a consultant appointment.

These findings offer significant opportunities for improved resource utilisation with a reduction in consultants follow-up appointments freeing up additional appointments to reduce waiting times.

Current business as usual referral statistics to the Stobhill Breast Service comparing 2014/15 and 2015/16 show an increase of 371 patients with 2832 patients referred in total in 2015/16, with clinic slots showing a capacity difference of -1160.

Evidence from the pilot also show that image-led follow-up could be acceptable to more patients if they were fully prepared for the self management pathway at diagnosis.

Within the constraints of the project patients were only made aware of the new model 2 weeks before their existing appointment. If the patients received a Macmillan Recovery Package HNA at diagnosis and an information pack on the image-led follow-up pathway it is anticipated that higher numbers would not require a consultants appointment.

It is also anticipated that TCAT patients would not present at the clinics as regularly. However it was not possible to evaluate this reduction in hospital contact during the scope of the current pilot.

An evaluation of the health economic impact of the pilot could be carried out at a later date however the information required to carry this out was not available from NHSGGC at this point in time.

DRAFT  
Confidential

*Clinical Staff within the Breast Service at Stobhill had a good understanding of the rationale for the project, including improvements to patient experience, service integration, co-ordination, and efficiencies...*

All staff within the Breast Team at Stobhill fully participated in the design and delivery of the pilot and now demonstrate a strong commitment to image-led follow-up. Staff took part in the operational group and a number of one-to-one interviews with the TCAT PM and demonstrated a clear understanding of the rationale for the programme with the most commonly cited statements shown in the diagram below:



# HEALTH AND SOCIAL CARE INTEGRATION

*Working with the TCAT project and the breast team in Stobhill has been an incredibly positive experience. The working relationship that has been forged and nurtured with our charity has shown real benefit to patients in increased access to services. I believe the project will be a catalyst for change in how the NHS and third sector work together going forward with improved benefits for all parties*

*BCC Director*

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**Confidential**

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4

## *Breast Cancer Care Glasgow Stobhill*

### *Moving Forward course November 2015 – May 2016...*

These are the evaluation findings of the Breast Cancer Care Moving Forward Course, held in partnership with Stobhill Hospital between November 2015 – May 2016. During that time there have been 2 courses at Stobhill and 24 patients have attended in total.

The overall aim of the course is “to enhance the provision of existing local support services on a range of topics affecting people living with breast cancer after diagnosis and during recovery”.

Since the Stobhill Breast Team introduced the TCAT project in October 2015 we have seen numbers on the course increase from 5 in May 2014 and 8 in November 2014 to a consistent average of between 12-15 attending.

#### **Clients top expectations for the course:**

- Meet with other women who have similar experiences
- Regaining self confidence
- Information and advice on how to move forward

The evaluation has combined qualitative and quantitative methodologies. We received 17 pre-course and 18 post-course questionnaires during the evaluation period. By comparing the average score across both forms we hope to understand to what extent the ‘average participant’ has achieved this aim.

The course includes sessions run by Breast Consultant Surgeons and CNSs at Stobhill.

Given the increase in numbers being referred by the Stobhill TCAT project, we have now increased the amount of planned courses to be delivered at Stobhill per year from 2 to 4.  
BCC Director

*“I don’t think this course could be any better”*

*“I learned a lot over the course of the 4 weeks”*

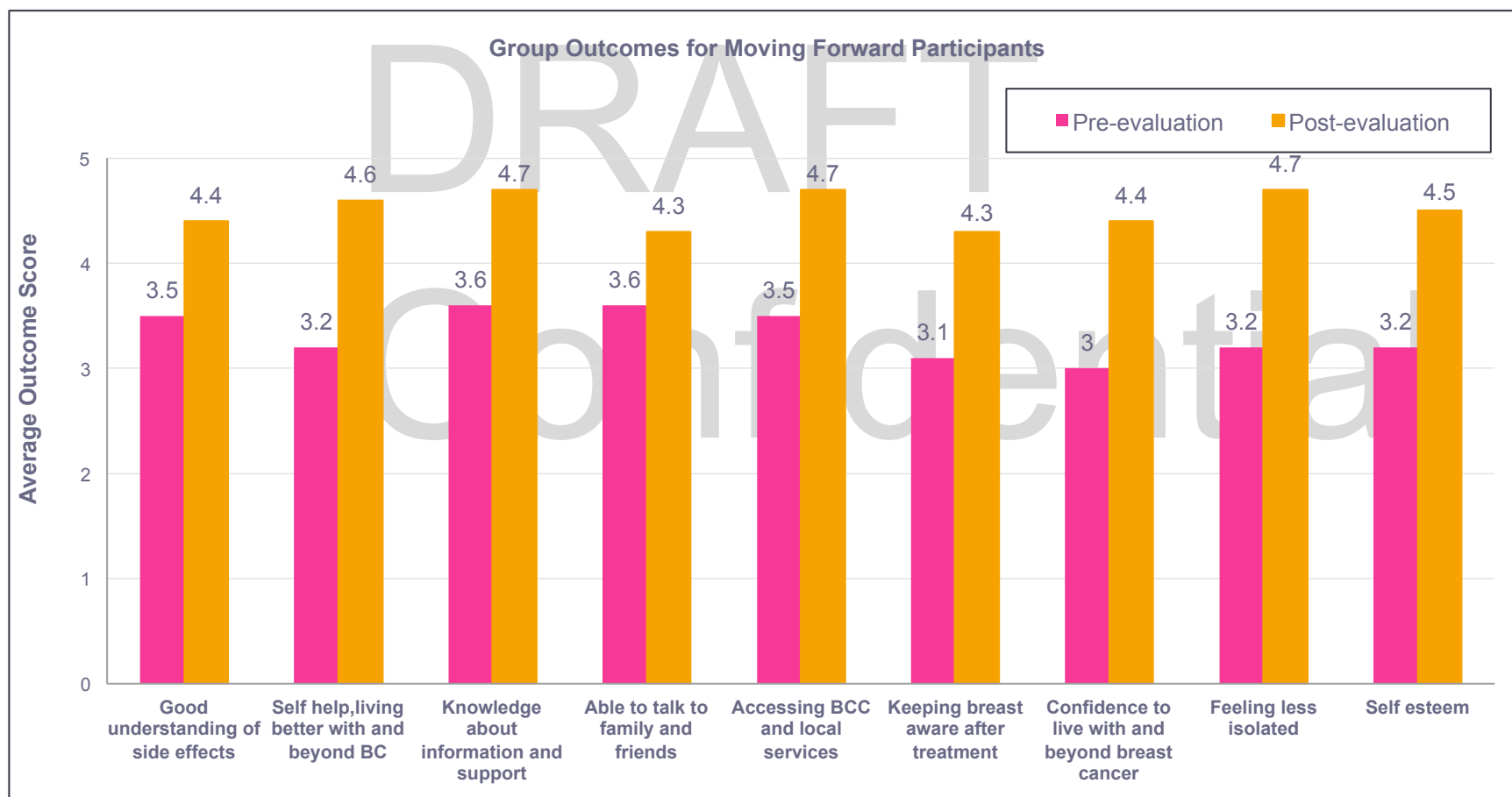
*“I think you have got the course just right”*

*“Course covered everything related to breast cancer and my well being”*



## Moving Forward Course Outcomes...

There has been a significant increase in referrals to Breast Cancer Care's Moving Forward course over the course of the TCAT pilot. All patients in the pilot have been offered the opportunity to attend the Moving Forward Course and although not all patients have wanted to attend a group session those that have seen significant benefits as outlined in the graph below. It is recommended that this partnership carries on and that the relationship is formalised at an operational level as BCC have the resources to provide significant health and wellbeing support during the follow-up pathway and can support hospital staff to improve follow-up care.



## *Improving Your Cancer Journey...*

Improving Your Cancer Journey (ICJ) is a new support service that has been in place since August 2014 and is being delivered by Glasgow City Council in partnership with NHSGCG, Macmillan Cancer Care Support, Glasgow Life, Cordia and Prostate Cancer. ICJ are able to offer a HNA and ongoing support to cancer patients within the Glasgow City area. ICJ can support patients wider financial, employment and lifestyle concerns.

As part of the TCAT project a new referral pathway was build with the Stobhill Breast Service and the ICJ team are now based onsite at Stobhill on a Thursday to support referrals directly from Thursday clinics. This service has been available since May with initial figures for that month outlined below.

The figures for the period 5<sup>th</sup> of May to 9<sup>th</sup> of June 2016 are:

	Patient Number
Referrals from CNS within Glasgow	15
Referrals from CNS out with Glasgow	8
Macmillan HNA completed	5
Engagement with existing clients	10
Adhoc clients	7

This partnership is still in its early stages however the CNSs are now promoting ICJ and referring directly to the Thursday session using a new referral form. ICJ write to patients 6 weeks after diagnosis, however many of the TCAT patients had not responded to this letter. The TCAT pilot where CNSs promote ICJ based on patient concerns recorded on the BHNA has seen 100% increase in referrals to ICJ.

Some concerns were raised by the CNSs around equity of care as this service is only available to Glasgow City patients and this is an area that should be looked at in more detail in Phase 3 of the project.

# REFLECTIONS AND LEARNING

# DRAFT

*“The programme has engendered a cultural change and developed a strong commitment from clinical staff”*

*TCAT PM*

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# Confidential

# 5

## Lessons Learned

- A longer timeframe is needed. The Phase 1 project has been a first step towards patient led follow-up and has provided proof of concept but the original bid should have been 2 year instead of 1 in order to fully evaluate the patient journey with the same cohort. This would be a more realistic timeframe to embed and sustain the image-led model into normal practice.
- The project manager role has been instrumental in driving the pilot and providing a link to the national TCAT programme, Local Authority and 3<sup>rd</sup> sector support organisations. Initial delays in appointing a PM in the first quarter of 2015 posed a significant risk to the project. Phase 1 of the pilot would not have been implemented without this resource.
- There is a need for transitional resource and funding to improve and embed the image- led pathway.
- Review of TCAT staffing resources.
- Robust patient led IT systems need to be in place to support the pathway.
- There needs to be a recognition that the proposed change is not just systemic but also cultural.

Despite all of the successes there have been some challenges to the development of the project. Changing staff onsite mean that local teams need the support of the wider stakeholders to ensure:

- Resources/funding – staffing resources are stretched and support is needed to free up resource to design and develop the TCAT model.
- Support for cultural change with on-going communication with clinical staff on the aims of TCAT being crucial to the success of the next stage.
- Corporate memory is maintained to keep momentum going.
- Systems embedded operationally to ensure they are sustained and not reliant on individual staff members who may leave.
- Support systems to minimise the use of paper based systems to ensure that the new processes are “joined up” – paper based systems are not sustainable for roll out.
- Clear preparation for the patient led pathway at the point of diagnosis to ensure that patient expectations are managed.
- Avoidance of duplication of work with support organisations such as ICJ when introducing the Macmillan Recovery Package HNA. As well as regular meetings with partner organisations.
- Adequate time slots for mammograms. The current TCAT timeslots are not sustainable.

## Recommendations

The Phase 1 pilot provides proof of concept and has had significant success in achieving the aims laid out at the start of the evaluation. However this is not long enough to embed image-led follow-up into normal practice and to ensure quality and safety are maintained. It is also important that momentum and staff commitment are maintained:

1. Application for Phase 3 funding to improve the pathway and move to sustaining and embedding patient led follow-up into normal business.
2. Continued project manager resource for an additional year to ensure momentum is maintained and Phase 3 is implemented using PDSA model.
3. BCC is sited as the main 3<sup>rd</sup> sector form of support for Breast Cancer Patients at Stobhill - Moving Forward Course built in to the patient pathway.
4. Embedding and rolling out the image-led model to newly diagnosed patients and those in 2–10 year annual follow-up.
5. Introducing the Macmillan Recover Package including Concerns Checklist, Care plan and Treatment Summaries.
6. Review of the BHNA tool.
7. Longitudinal study with the same cohort of patients.
8. Implementing electronic systems (TSUM and patient led database) to support both of the above.
9. Highlighting the successes of the Stobhill project to prove that patient led follow-up works and is acceptable to patients.

### Longer term outcomes

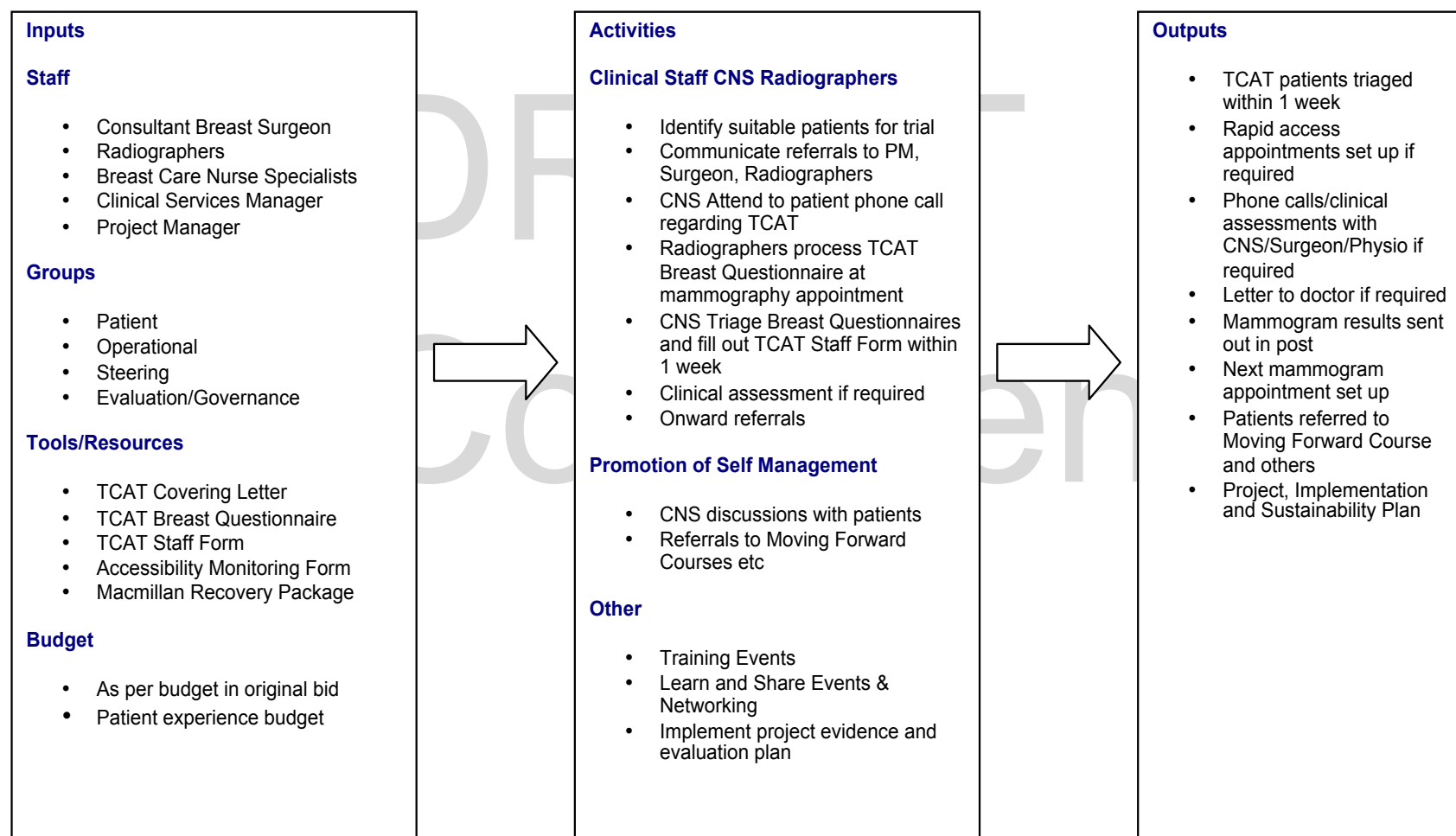
- Over 2000 People affected by breast cancer have an increased and improved level of appropriate support which replaces unnecessary contacts with secondary care and ultimately improves quality of life.
- Stobhill hospital becomes a gold standard of patient led follow up that can provide a roadmap for roll out across the wider region.
- Project continues to support national Patient Experience Quality Performance Indicators.
- Further improvements in resource utilisation resulting in a more efficient service.
- Improved health and social care integration across all sector. This would involve building on the incremental improved communication with 3<sup>rd</sup> sector but in addition improving communication with patients and GPs.
- Clinical team are supported to further implement the Macmillan Recovery Package.

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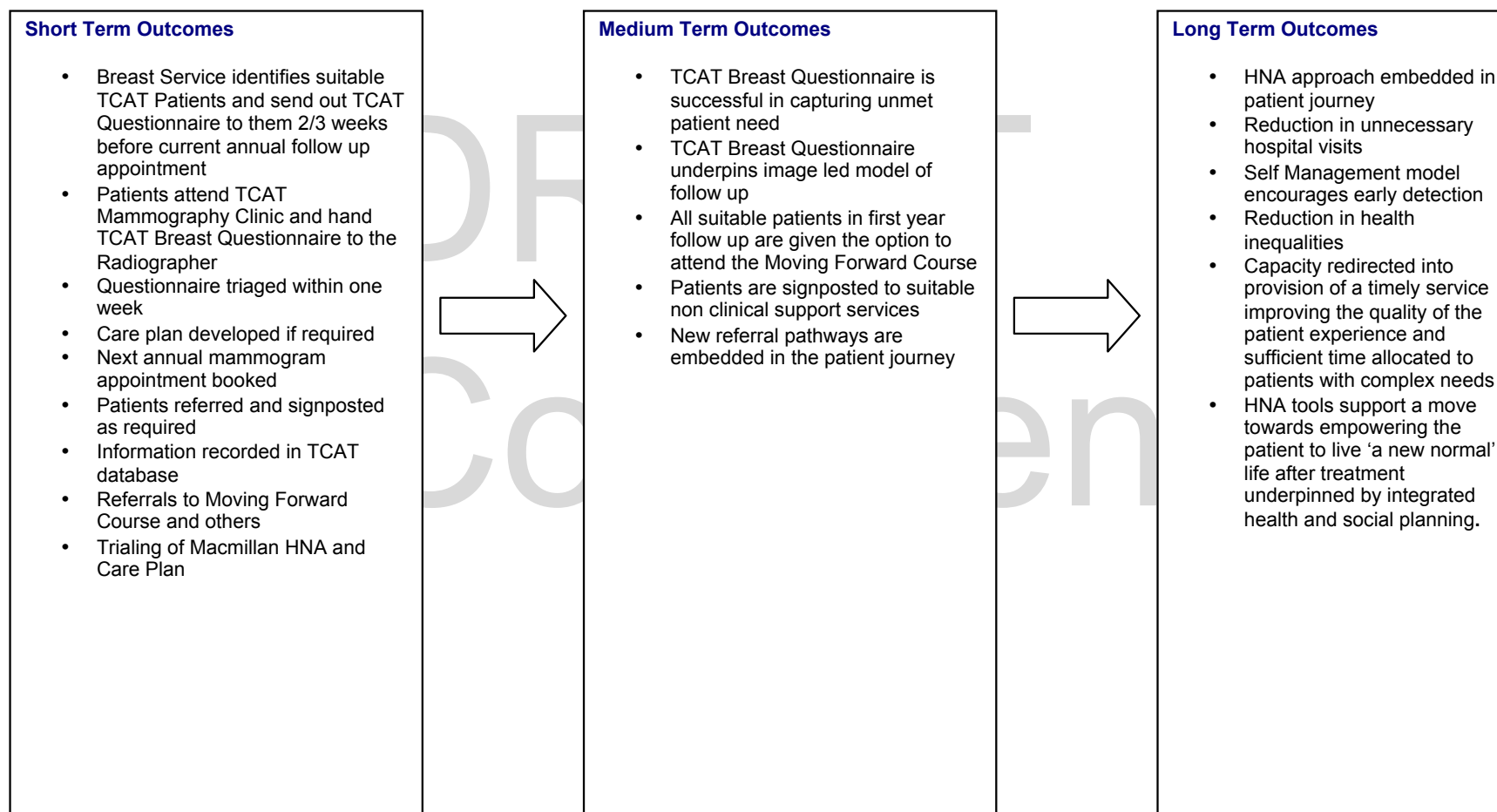
## Appendix 1

### NE Sector Breast Team – Move to image led/ self management led model of follow up



## Appendix 1

### NE Sector Breast Team – Move to image led/ self management model of follow up





## Appendix 2



Dear

As part of your breast cancer treatment follow up you are due to attend your annual outpatient clinic appointment at Stobhill Hospital.

**We are currently reviewing our breast cancer follow up service and patients commencing follow up are no longer required to attend their existing clinic appointment. We are instead asking you to attend a new clinic appointment specifically for a mammogram. Please see details of your new appointment below.**

**Please ignore any automated text messages you receive for your original appointment.**

We are also asking you to complete the enclosed questionnaire with information on what has happened to you and how you have been since your treatment finished. You can then bring it with you to your mammogram appointment to hand to the radiographer.

If you raise any concerns within the questionnaire we will contact you and arrange for you to see an appropriate healthcare specialist within the team.

**Please attend your new mammogram appointment on:**

**Date: Wednesday**

**Location: Imaging Department, First Floor, Stobhill Hospital.**

Your questionnaire feedback will help us understand any concerns and feelings you have. It will also help us identify any information and support you may need. It will only take a few minutes to complete. The questionnaire is optional and if you decide not to complete it, this will not affect your care. The information you provide will be treated confidentially.

**If you do not wish to take part in our questionnaire and wish to keep your current clinic appointment, or the above appointment time is not suitable please can you telephone Lena Oswald 0141 355 1476 or Mary McGlade 0141 355 1477 to let us know.**

If you would like this questionnaire in another language, an alternative format, or help to complete it then please call one of the numbers above.

Yours sincerely

Mr Keith Ogston and Ms Margaret MacLean  
Consultant Surgeons  
Stobhill Hospital

## Appendix 3



### Identifying your concerns

We are interested in learning more about how you have been since your last breast follow-up or hospital visit.

This self assessment is optional however it will help us understand any concerns and feelings you have. It will also help us identify any information and support you may need in the future.

If any of the problems below have caused you concern in the past week, and you wish to discuss them please call one of our Clinical Nurse Specialists - Lena Oswald 0141 355 1476 or Mary McGlade 0141 355 1477

Name .....  
Address .....  
.....  
CHI .....  
Label or address from IT system

Date form completed .....

**Please complete the following questions and give to the radiographer at your mammography appointment**

1. In general, would you say your health today is (please tick one box):

- Excellent  
 Very good  
 Good  
 Fair  
 Poor

### Since your last breast follow-up or hospital visit

1. Do you have any concerns about your cancer treatment? Y  N
2. Do you have any concerns about your treatment? Y  N
3. Have you already had a mammogram? Y  N
4. Are you aware of changes in any of these areas since your last review?
- |          |                            |                            |
|----------|----------------------------|----------------------------|
| Skin     | Y <input type="checkbox"/> | N <input type="checkbox"/> |
| Chest    | Y <input type="checkbox"/> | N <input type="checkbox"/> |
| Nipple   | Y <input type="checkbox"/> | N <input type="checkbox"/> |
| Arm      | Y <input type="checkbox"/> | N <input type="checkbox"/> |
| Armpit   | Y <input type="checkbox"/> | N <input type="checkbox"/> |
| Shoulder | Y <input type="checkbox"/> | N <input type="checkbox"/> |
5. Do you have new or unusual pain? Y  N
6. Do you have new or unusual lump(s)? Y  N
7. Have you noticed something else new or unusual? Y  N

## Appendix 3

**Please describe this change(s) here:**

8. Is there something worrying you about your past treatment?    Y     N

**Please describe your any concerns you have here:**

9. Would you like to speak with someone about your concerns?    Y     N

**Other concerns**

10. Is there something worrying you that is not covered in this form    Y     N   
e.g. practical, family, emotional, financial

**Please tell us about any of these worries here:**

**Do you find the questionnaire:**

1. Easy to understand                    Y     N
2. Easy to read                            Y     N
3. Helpful to record your concerns    Y     N

4. If you have any comments on the questionnaire please write in the box below

## Appendix 4

**TCAT Staff Form**  
For official use only

**Radiographer**

Patient requires further action: Y  N

Additional  
Information: \_\_\_\_\_

**1. FORM REVIEW – Further action**

Reviewed by	Name	Position	Date reviewed

No concerns got to point 2.

Concerns - Action:

BCN  | Surg  | Onc  | Physio  | GP

More information:

Phoned patient  Date/time \_\_\_\_\_

	Attended	DNA	2nd Appointment
Breast Care Nurse			
Surgical			
Oncology			
Physio			
GP if DNA			

2. Result letter sent to patient/copy GP   
Next mammogram appointment booked