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The views expressed in this report are those of Edinburgh Napier University researchers and do not necessarily represent those of Macmillan Cancer Support and their partners.

This report may be subject to change

EXECUTIVE SUMMARY

The Transforming Care after Treatment programme is a partnership between the Scottish Government, Macmillan Cancer Support, NHS Scotland and Third Sector organisations that seek to improve the after care and support for people living with and beyond cancer. Edinburgh Napier University was commissioned by Macmillan Cancer Support, on behalf of the programme partners, in June 2014 to undertake an independent evaluation of the programme and to gather learning and insights to inform the programme's implementation.

The specific objectives for the overall evaluation include:

- provide regular findings that help us to test whether the programme is helping to achieve better outcomes and experience of after care for people with cancer and better resource utilisation
- draw out lessons learned on what works (and what doesn't work), for whom, why and in what circumstances – to shape the development of the programme and inform future phases
- work collaboratively with the projects and key partners to share learning, and support key stakeholders to understand what the findings means for them;
- support the self-evaluation of the projects to enable them to provide robust and credible evidence that can be used locally to support future sustainability and also influence post treatment care regionally and nationally
- Where possible and appropriate, support the use of the evaluation outputs and findings to further influence and encourage buy-in for the TCAT programme and its aims from local, regional and national stakeholders

This report is the first output and presents early findings of *scoping* work based on data gathered through qualitative interviews with 11 stakeholders who sit within the governance structure of the programme, 7 focus groups with project teams (n=37), meetings with project teams and a review of all the documentation associated with the programme Whilst our analysis remains on-going the purpose of this first report as set out in the commissioning documents is to:

- provide an overview of the TCAT Programme
- present the learning to date; and
- set out next steps and recommendations for the national programme evaluation.

Findings from the scoping work

The findings from the interviews with stakeholders and phase 1 project teams identified a number of themes:

The meaning of 'after care' and 'transformation': This related to the variety of meanings associated with the term "after care" among stakeholders and projects. Some believed that to ensure comprehensive care after treatment, this 'care' has to start at diagnosis.

The scope of TCAT: A number of stakeholders and projects raised some concerns about the scope of the TCAT programme; using terms like "*trying a bit of this, trying a bit of that*" "*trying to do everything*" "*bit too complicated*"

TCAT structures and design: The TCAT programme design is multi-layered and multi-faceted. It includes a Macmillan Programme Manager, a Programme Board, and Evaluation Advisory Team, Macmillan Development Managers, regional network TCAT Clinical Leads and Project Managers and latterly the evaluation team at Edinburgh Napier University. This design has both positive and negative impact on the projects teams, stakeholders and outcomes to date.

Early development and implementation processes: Early implementation challenges were identified from all the participants and included the continued 'paperwork' requirements, local and regional capacity for administration and in some cases, project management, recruitment delays and IT issues.

Partnership working and integration: There is early evidence that TCAT has initiated moves towards partners getting round the table to examine their potential and future role in the after care of people affected by cancer. Stakeholders and local projects see TCAT as providing tangible opportunities to pursue integration and partnership around services for people with cancer and a vehicle to focus on the wider integration agenda.

Sustainability of TCAT: A primary aim of TCAT is to embed a sustainable approach to after care services. The TCAT programme has been designed to ensure the Cancer Networks have a key role in sustainability and roll out. Some stakeholders commented upon the scale of this future role and the local and national challenges such work would give rise to.

The role of patients and carers in TCAT: The work to date to incorporate the patient voice has been slow to come on stream within the national structure, thereby limiting its influence during the early phase 1 stages. Overall the role of patients and carers within the TCAT programme at all levels requires clarification and prioritisation.

What is working well and what is not working so well?

Based on the three parts of the scoping work: qualitative data, document review and support the following are a summary of reflections from the Edinburgh Napier University Evaluation team on what is working well, what is not working so well and lessons that can be learned to date to inform the programme

What is working well?	What is not working so well?
Opportunities that come from diversity of local projects and bottom up approach	Clarity around the key aims of overall programme at all levels
Local ownership of projects	Impact of different meanings and emphasis placed on terms 'after care' and 'transformation
Establishment of a support structure	Scale of expectations and anticipated outcomes
Potential to learn and share	Current approach to 'learn and share' components of TCAT
Local individuals being linked to TCAT governance structures	Slow build up and variability of programme structures at regional level
TCAT Champions	Administration processes relating to application and early implementation
Established positive base for future integration and partnership	Actual implementation of integration and partnership working
Capitalising on history of joint working at a local level in some areas	Capacity at all levels of TCAT programme
Commitment to ensuring a key influential role for patients and carers	Vulnerability of patient voice within TCAT and limited / stalled action to date
Senior level engagement in TCAT in some areas	Less focus upon risk stratified care than on other TCAT development priorities
Added value from being part of a national programme	Limited plans for enhancing potential for sustainability

Lessons learned

Making it happen: Project teams have demonstrated a strong commitment to driving forward changes in the way they work. As projects move to the next stage and engage with patients/clients in these new ways of working, it is important they acknowledge the processes to date and learning from some of the challenges that emerged from the application, partnership agreements, capacity and future reporting processes.

Increasing involvement: There is still work to be done to further clarify the role of the TCAT Cancer Experience Panel and specifically our engagement as evaluators. The key to the programme is making the voice of people with cancer visible in the decision making processes of the individual projects. This is not to be prescriptive, rather to ensure consistency but also to acknowledge the vulnerability of this panel.

Be realistic around timeframes: The programme has clearly defined timelines and is also evolving. Many of those interviewed felt timelines were a challenge. Through this process many have reflected on how far they have come and how much they have learnt. It is important that phase 2 are aware of intelligence gathered to date.

Looking inward and outward: Although it has been necessary to focus energy towards how things should develop, it is also important to have the foresight to have a message that's going out which will reinforce and acknowledge the work that people are doing.

Managing expectations: There are a number of expectations of individual projects, stakeholders and the evaluators. Re-visiting the original objectives in light of the scoping work may be timely as the programme moves into Phase 2.

Balancing competing demands: The connectivity between services is often well established and changes, however minor, can create ripples that impact beyond the initial plan. It is these unintended consequences of change that can create frustration and increase workload among individuals working on or supporting TCAT projects. Capturing these small but crucial elements are important to articulate.

Next steps and recommendations

Edinburgh Napier University will work with the Transforming Care after Treatment Programme board to move the overall evaluation to the next stage. It is anticipated the next steps will include:

- Establishing the timelines for data capture across the projects
- Introducing a core minimum dataset across the programme, recognising diversity while also acknowledging common elements
- Ensuring the voice of people who receive the new service/intervention is clearly gathered across the programme
- Continuing to explore the changing views, experiences and knowledge of stakeholders and project teams as the programme evolves
- Identifying the evaluation support needs of project teams moving forward.

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INTRODUCTION

The Transforming Care after Treatment (TCAT) programme is a partnership between the Scottish Government, Macmillan Cancer Support, NHS Scotland and third sector organisations that seek to improve the after care and support for people living with and beyond cancer. This is an ambitious and exciting initiative with 11 projects across Scotland launched in phase 1, and further projects joining the programme in phase 2 and 3 across a 5 year period.

Edinburgh Napier University (ENU) was commissioned by Macmillan Cancer Support, in June 2014 to undertake an independent evaluation of the programme and to gather learning and insights to inform implementation and evaluation.

The specific objectives for the *overall evaluation* are to:

- provide regular findings that help us to test whether the programme is helping to achieve better outcomes and experience of after care for people with cancer and better resource utilisation
- draw out lessons learned on what works (and what doesn't work), for whom, why and in what circumstances – to shape the development of the programme and inform future phases
- work collaboratively with the projects and key partners to share learning, and support key stakeholders to understand what the findings means for them;
- support the self-evaluation of the projects to enable them to provide robust and credible evidence that can be used locally to support future sustainability and also influence post treatment care regionally and nationally
- Where possible and appropriate, support the use of the evaluation outputs and findings to further influence and encourage buy-in for the TCAT programme and its aims from local, regional and national stakeholders

A detailed set of overall national evaluation questions that underpin these objectives are attached in Appendix 1.

This report is the first output and presents early findings of scoping work undertaken by Edinburgh Napier University between June and December 2014. The specific aims of the *scoping work,* reported here, were to establish professional working relationships with project teams and the wider stakeholders and to gather data that informs the overall evaluation.

Our specific objectives were to:

- understand the governance structures and establish relationships with the Phase 1 projects, regional networks, TCAT Cancer Experience Panel and various stakeholders
- establish an evaluation support structure for the projects
- undertake baseline focus group discussions with the Phase 1 projects (prior to commencing their projects) to explore their experiences, expectations, attitudes and behaviours
- undertake interviews of a sample of stakeholders
- begin to identify process, impact and economic measures that can inform the overall evaluation.

The report is structured in seven sections.

Section One: Background and context

This section presents the background to the TCAT programme in Scotland, the evidence driving changes in the provision of after care services for people with cancer, and cancer projects for Scotland.

Section Two: **Methodology**

Presents the evaluation approaches underpinning our work and the methodologies used in our scoping.

Section Three: Scoping findings

Through the presentation of the results of our scoping work this section sets out the current position of the TCAT Programme and highlights the benefits, sources of added value, possible drawbacks and challenges. As both our *scoping* (reported here) and *overall evaluation* adopts realist and appreciative inquiry approaches there is a deliberate focus on what works well and what is not working so well to date.

Section Four: Document review

As many of the “impact” related evaluation questions cannot be answered at this stage we list the key components of TCAT programme and present a descriptive profile of the phase 1 projects

Section Five: Edinburgh Napier University support

From our work to date we set out our conclusions to date and draw out early lessons learnt to date for the TCAT programme and wider stakeholders.

Section Six: Lessons learned

Edinburgh Napier University provide reflections on what is working well, what is not working so well and lessons that can be learned to date, to inform the evolving TCAT programme.

Section Seven: National evaluation: Next steps and recommendations

Proposes the next steps of the evaluation work overall. These steps recognise the individuality of the projects, our role in evaluation support and the importance of gathering specific data to inform the overall evaluation.

SECTION ONE: CANCER IN SCOTLAND

Introduction

The increasing numbers of survivors, pressures on traditional aftercare services within the NHS, and the opportunities afforded Scotland to work in an integrated way between health and social care has provided the impetus to embrace new models of care and ways of working that support people living with cancer. This section provides some background to the numbers of people living with cancer now and into the future, what living with a diagnosis may mean to someone and the policy drivers that influenced the development of the 'Transforming Care After Treatment' programme.

Trends in cancer incidence and survival

Cancer is a disease that affects many of us. There are over 200 different types of cancer and it is estimated that more than 2 in 5 people in Scotland will develop some form of cancer during their lifetime, and that around 1 in 8 males and 1 in 11 females will develop some form of cancer before the age of 65; while after 65 the risk of developing cancer increases[1]. In 2012, 30,450 people in Scotland were diagnosed with cancer and overall trends suggest numbers will rise further in the future.

Over the last twenty years, almost all cancers have shown improvement in survival five years after diagnosis, coupled with decreased cancer mortality in the past 10 years [2]. This means increasing numbers of people are surviving cancer and living up to and beyond five years. Across the United Kingdom, it is predicted that numbers living with a previous cancer will increase from 2 million to 4 million by 2030. In Scotland this would be an increase from 190,000 in 2010 to around 340,000 by 2030 if current trends continue [2,3].

These increases are multifactorial; however cancer prevalence in Scotland increases with age and the population is aging everywhere in the UK[4]. Of those diagnosed with cancer presently, 65% of males and 56% of females are aged 65 or over. Coupled with the knowledge that many of the 65 and over age group have co-existing diseases (co-morbidity), the potential demands placed on health and social care resources present challenges for these particular providers now and into the future[5].

Data on healthcare utilisation indicates that the first year and the last year of life shows the highest quantity of cancer-related acute healthcare usage. However, there is also a significant level of usage in the period 1-5 years after diagnosis[6]. Based on projections, this population and those living beyond five years will increase significantly. This will impact on health and social care requirements and has been one of the drivers to establishing the transforming care after treatment programme to consider new ways of working to meet the needs of this population.

Living with and beyond a cancer diagnosis

A Cancer diagnosis evokes a sense of fear among the population and many view it as a life-limiting condition. The term cancer *survival* is reported as a core measure of cancer outcomes and often refers to the population of cancer patients who live *disease-free* for at least 5, 10 or years after treatment. Unfortunately there remains under-reporting and limited data about the state of health and well-being of cancer survivors, the specific problems, concerns or needs at different times after diagnosis and at different phases in the pathway of care.

Macmillan Cancer Support[8] (p 69) refer to the concept of survivors as "… *someone who has completed initial cancer management and has no apparent evidence of active disease, or is living with progressive disease and may be receiving cancer treatment but is not in the terminal phase of illness (last six months of life), or has had cancer in the past".* It recognises that patients may require support and opportunities to rehabilitate at different stages in the cancer pathway and that aftercare may not occur in a uniform way (for example patients may present with progressive disease at diagnosis and may not live disease-free).

The transition from diagnosis and initial management to follow-up and monitoring can be a particularly difficult time for those with cancer. Many struggle with the transition and describe a sense of vulnerability and loss of frequent medical monitoring and support as abandonment [9]. Survivors are reported as being in poorer health and have more psychological and functional disability than those without a cancer diagnosis, and this is even higher among those who have additional co-existing diseases[10].

The consequences of cancer and its treatment are far reaching and very individual. Day to day activities such as shopping, driving, sleep, and the ability to work and travel can impact on a person's self-esteem and confidence. Many need help to deal with fears of recurrence and rebuild their confidence, deal with others' expectations that life should be 'back to normal' and adjust to expectations about changes in their physical ability[11,12]. It has been argued that regaining lost self-confidence is an important aspect of recovery alongside physical and psychosocial problems, and requires a supportive framework to promote rehabilitation and self-management [12] one that views an individual holistically and integrates support from both health and social care, to maximise recovery. This approach moves away from trying to manage all aspects of cancer recovery within an acute, hospital based follow-up setting, towards a shared care approach; supporting the individual to adapt to the chronic changes that may be associated with cancer and its treatment, closer to a person's home and the community where they live but also enable individuals to take control of their own lives.

Cancer policy in Scotland – drivers for change

The Scottish Government, through the Better Cancer plan[8] set out a series of actions to inform the direction of cancer services into the future. It acknowledged that an ageing population, treatment advances and earlier detection of some cancers meant more people would be living with a diagnosis of cancer, and for longer. Cancer is increasingly seen as a long-term condition; individuals face uncertain outcomes, treatments are extended over long periods and these may be interrupted with relapse, further treatment and recovery. Therefore, the traditional way aftercare services have been delivered in the NHS will also need to change to reflect this altering picture. The plan was a catalyst for the establishment the Living with Cancer Group. They were tasked to consider how the voluntary and statutory sector could work together to best meet the needs of this population.

In 2010[13] clear areas to improve access to cancer services were identified by the group. These included information, support and self-management activities that would empower individuals to make decisions about their own health. These aligned well with the NHS Healthcare Quality Strategy that services are person-centred, safe, effective, efficient, and equitable and timely.[14] However, achieving these changes within the finite resources available required new partnerships and ways of working between healthcare, social care and voluntary sector providers. The Cancer Taskforce, with responsibility for the delivery of the cancer plan, sought to strengthen the role of the Regional Cancer Networks and encourage increased collaboration between NHS Boards, Government Health Departments and the Third Sector. The Transforming Care after Treatment Programme[15] was the culmination of this collaboration and partnership working.

It aims to improve the after care and support for people living with and beyond cancer through three key goals:

- initiate and **embed** an integrated and sustainable approach to the provision of care involving **health, social care and third sector** partners that drives a shift in focus from treating the disease **to health and wellbeing**

- create a **culture of confidence** in people affected by cancer and professionals, which supports people to **regain control** of their lives, facilitates self-management, develops new approaches to **surveillance** and reduces **unnecessary reviews**

- Facilitate the establishment of **shared decision-making with people** affected by cancer in cancer follow-up programmes that promote **co-design** of high quality, safe and **person centred care**.

The Scottish Governments programme to reform the integration of health and social care will seek to join-up health and social care services, especially for those with long-term conditions and who may be elderly.[16] This reform aligns well with the demographic profile of cancer survivors and the ambitions of the TCAT programme to improve services for people with cancer irrespective of health or social care setting.

The legislation to allow Health Boards and Local Authorities to begin the process was passed on the 25th Feb 2014 and any changes are still in their infancy. Health boards and local authorities can now choose to proceed with a model based on the one that best suits their local needs[16 (p2,4)].

"The first model of integration allows for Health Boards and Local Authorities, working with health and social care professionals, the third sector, users, carers and other key stakeholders, to establish an Integration Joint Board, to which the Health Board and Local Authority delegate the responsibility and resources for adult health and social care".

"The second model of integration outlined in the Bill allows for either the Health Board or the Local Authority to take the lead in planning and delivering adult integrated health and social care service provision in their area".

One of the aims of the TCAT programme is in its vision to embed a culture of partnership working across the projects, aligning the new models of care with the health and social care integration policy. However, how these large scale changes enable or inhibit the implementation of TCAT will become apparent as it evolves.

New pathways of care for cancer survivors

It is only in recent years that an emphasis has been placed on aftercare and survivorship. The evidence base to support new models of care for this population is still developing through a number of flagship projects across the UK. Some of these are:

The National Cancer Survivorship Initiative (NCSI) England[17]

- Northern Ireland Cancer Survivorship
- One to one implementation support programme
- Evaluation of electronic holistic needs assessment (eHNA)

Building on the intelligence gathered over the past four years through the National Cancer Survivorship Initiative, a number of key interventions that could make an immediate difference have been identified based on the recovery package; using structured holistic needs assessment and care planning; treatment summaries; patient education and support events; advice about and access to support about physical activity and healthy weight management. In addition, they have strengthened the evidence in the area of rehabilitation and its importance in supporting recovery back to work, education, preventing ill health and confidence building.

There are a number of other initiatives underway in Scotland by both Macmillan Cancer Support and other organisations to empower individuals to take an active role in their aftercare. These include the Scotland wide “Where now? Maggies” offered by the Maggie’s Cancer Caring Centres, Moving Forward offered by Breast Cancer Care and a number of other initiative led by Macmillan Cancer Support including; eHolistic Needs Assessment, health and wellbeing clinic pilot, Glasgow Life, and the Glasgow improving your cancer journey , Steps to recovery, Move more and Macmillan welfare benefits. It is likely more will emerge as this population of cancer survivors gain more prominence.

The Transforming Care after Treatment Programme

The TCAT programme was launched in July 2013. Nationally, TCAT is managed by a Programme Board and a full time National Programme Manager and will continue for 5 years. A national governance framework is in place to support the TCAT programme. This includes a Programme Board with 24 members, an Evaluation Advisory Group and an Operational Group, both of which have 13 members. Also part of the programme is a Service User Involvement Manager and the TCAT Cancer Experience Panel.

Within the TCAT Programme, the Regional Cancer Networks (NOSCAN, SCAN and WoSCAN) have an important role. These networks are collaborative groups covering a number of NHS Boards over a defined region to ensure there is equitable provision of high quality clinical services for individuals with cancer.

The Cancer Networks are tasked with “supporting and driving the TCAT programme forward”.[1] Funding was provided to the Networks to cover clinical release time and project administration.

At present SCAN and WoSCAN, both have a TCAT Programme Implementation Group and have staff and systems in place. NOSCAN do not and will re-advertise the post of TCAT Clinical Lead in January 2015.

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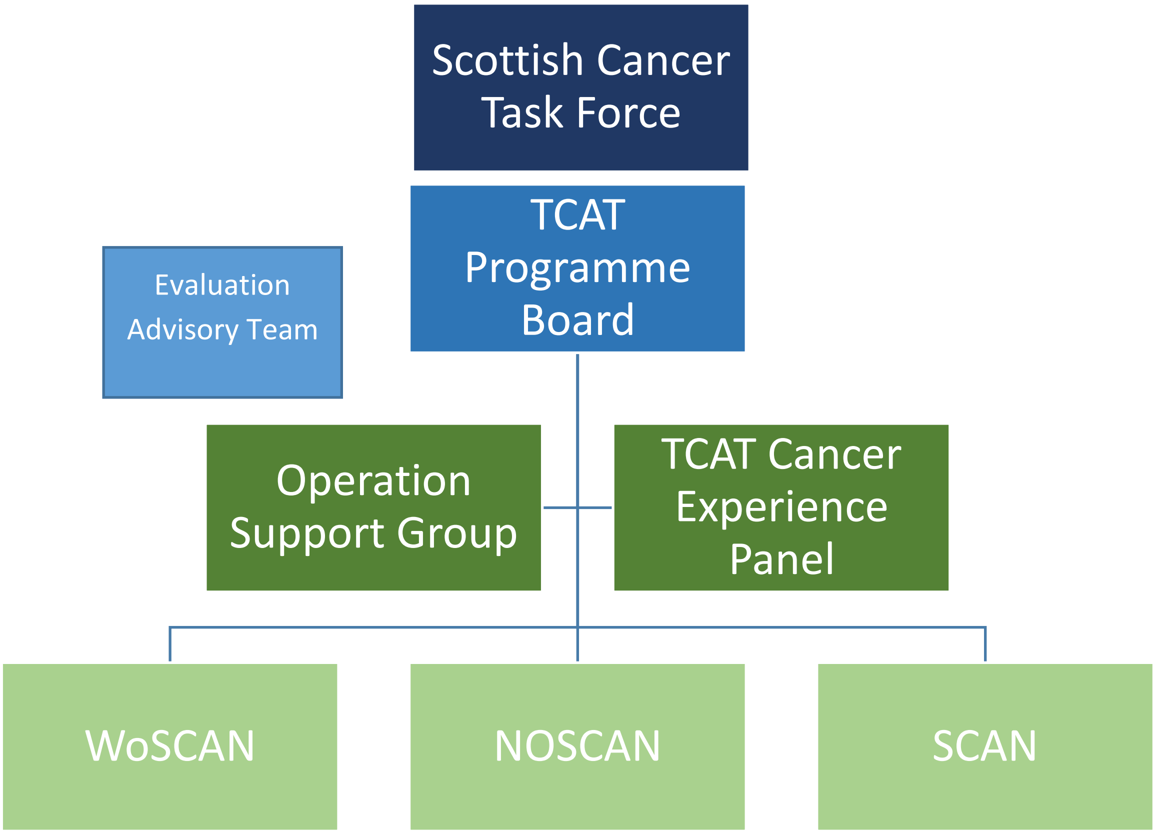
[1] Operational Guidance 11 July 2013

Figure 1: TCAT Structure and Design



Roles within the TCAT Structure[2]

The Programme Board: to provide national leadership in the shaping and delivery of the partnership between Macmillan Cancer Support and the Scottish Government to transform cancer care after treatment

TCAT Cancer Experience Panel: to innovate and strengthen the approaches used to involve patients, carers and the public in the development of the TCAT Programme and help the programme board to account for delivering improvement in patient experience

Operation Support Group: Supporting delivery across the 3 networks providing a mechanism for programme Manager and Network Project Managers to discuss delivery.

Cancer Networks Project Groups: definition, delivery and evaluation of projects. Supported by appropriate Project Governance Framework incorporating Network Leads, Managers, Macmillan Development Managers and appointed local Project Managers.

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[2] http://www.scotland.gov.uk/Topics/Health/Services/Cancer/TCAT/TCATterms

To achieve the set aims, the TCAT Programme Board is funding local development projects across Scotland. In December 2013, TCAT funded 11 local projects across Scotland, known as Phase 1 and each local project has its own advisory/steering group. The local projects have had a 6-9 month development phase with one of the first Phase 1 projects ‘launching’ in October 2014.

The Scottish programme uses a top-down and bottom-up approach. The top-down criteria were drawn from the previous National Cancer Survivorship Initiative[18] and include the components of the recommended recovery package.

As the introduction of these components within local projects was seen as crucial to the success of the TCAT programme, it was expected that at least one of the priorities would form part of any local proposal for funding.

- Holistic Needs Assessment
- End of treatment summaries
- End of treatment review points (such as health and well-being events)
- Cancer care review – within primary care
- Risk stratified follow-up care
    - Clear assessment of need
    - Process for monitoring people remotely
    - Co-ordinated rehabilitation providing education and support
    - Rapid person led access back to secondary care
    - Access to community based resources

Other elements prioritised for Scotland were the progression of health and social care integration and the involvement of patients and carers.

SECTION TWO: METHODOLOGY

This section describes the overall approach and methods used in our *scoping* and the work undertaken to date to support local project evaluations.

Our specific objectives were to:

- understand the governance structures and establish relationships with the Phase 1 projects, regional networks, TCAT Cancer Experience Panel and various stakeholders
- establish an evaluation support structure for the projects
- undertake baseline focus group discussions with the Phase 1 projects (prior to commencing their projects) to explore their experiences, expectations, attitudes and behaviours
- undertake interviews with a sample of stakeholders
- begin to identify process, impact and economic measures that can inform the overall evaluation.

Evaluation design

This evaluation adopts realist and appreciative inquiry approaches. Key components of these approaches involve understanding the context of the evaluation, the mechanism of action of any intervention and resulting outcomes. In addition there is a deliberate focus on what works well and understanding why this is the case and how success can be replicated and transferred within different contexts. It is essential that these theoretical approaches be translated into the evaluation design, methodology, data collection and analysis processes. Within this first phase of the evaluation several data collection activities have focused on understanding the context of local projects and the wider TCAT national programme. Introductory meetings and focus groups with local project teams, documentary analysis and interviews with stakeholders have all included a core focus of making sense of local and national contexts.

Data gathering has also sought to understand desired project outcomes and appreciate how these are to be achieved. Hearing the voices and perspectives of a wide range of people provides authenticity and richness to the evaluation findings. Introductory meetings with project teams have actively sought to appreciate the development and application of each project. There has been a direct focus on asking questions which promote understanding and clarification, celebrate positive developments but which are also curious about how each project will undertake effective evaluation. It will be important in the future to incorporate hearing the perspectives of people who are experiencing care after cancer treatment.

This individualised approach is consistent with realist and appreciative inquiry approaches. Utilising a case study approach as the evaluation develops will provide insights as to the mechanism of action of planned interventions. For example unpicking the key elements of how a holistic needs assessment supports self-management and partnership working between the person and the healthcare practitioner. This process of data collection will be important to following a realist approach. The evaluation design is structured to consistently ask questions which focus on appreciating achievements and identifying how success can be translated across the TCAT programme.

To inform the objectives of the scoping work, the different components are presented in this report under three headings.

- Scoping findings
- Document review
- Evaluation support to projects

Qualitative data gathering

A combination of focus group discussions with project teams (n=7) and individual in-depth interviews (n=11) with representatives of the governance structures (stakeholders) were undertaken.

Document review

The evaluation team familiarised themselves with the Phase 1 projects, their aims, proposed outcomes and the overall governance structures. Where available these included the minutes of programme board meetings, implementation steering group and cancer network meetings and each of the phase one project documents such as initial bids, minutes and partnership agreements.

Each project's expression of interest application was reviewed using a standardised proforma to help identify economic evaluation potential. In particular projects were evaluated for their interventions, opportunities for control groups/comparisons and relevant outcome measures such as quality of life measures using validated tools (e.g. EQ-5D or SF-36), and the amount of support required to generate these data. We will apply the same review process of selection for phase 2 and phase 3 projects.

Evaluation Support by Edinburgh Napier University

One of the key aspects of Edinburgh Napier University's *overall programme* evaluation is to '*support the self-evaluation of the projects to enable them to provide robust and credible evidence.'* This was undertaken as a parallel activity to our scoping but has also provided data for the initial findings.

Edinburgh Napier University approached our evaluation support role a number of ways.

- Facilitation of an evaluation workshop in June 2014

- Establishment of a support/advice mechanism with named point of contact within the evaluation team for each local project
- Face to face meetings with projects to understand the proposed local evaluation methods and approaches
- Establishment of an on-line Community of Practice site

Ethical approval

Ethical approval was obtained from Edinburgh Napier University internal committee to undertake the scoping work.

Limitations to the methodology

As Edinburgh Napier University's original proposal set out the need for this initial scoping work to inform the definitive approach to the overall programme evaluation, some limitations and challenges were expected.

- We are still completing our introductory meetings with some of the Phase 1 projects, in particular Highlands. However, they have been invited to the Evaluation learn and share event in March 2015.
- Three phase 1 projects were not able to meet our team or participate in the focus group discussions and therefore our findings from these groups are based on our review of the documents only.
- Edinburgh Napier University had hoped to hold focus group discussions at the evaluation workshop but this was not possible due to time constraints on the day. While this was a deviation from our original plan, undertaking them at a later date ensured more individual team members could participate as numbers on the evaluation workshop day were restricted.
- The timing of the appointment of Edinburgh Napier University (May 2014) meant that a certain amount of retrospective data gathering was required to inform the formative aspects of the evaluation. In this context the Edinburgh Napier University team considered face to face meetings were the most effective way to establish relationships and assigned a team member to each project.
- Focus group discussions with the TCAT Cancer Experience Panel and the Macmillan Development Managers are outstanding.

SECTION THREE: SCOPING FINDINGS

Introduction

To build a picture of the early experiences, expectations and thoughts of project teams prior to moving to the implementation phase, we invited 10 project teams to participate in a focus group discussion between September and December 2014 and 7 were conducted. To maximise the opportunity to include as many participants, where possible, we ran the focus group activity before or after a planned project steering group meeting. The number of participants in each focus group ranged from 2 – 8 (see Table 1).

Table 1: Number of participants in each focus group discussion

Project	Number of participants
Group 1	3
Group 2	2
Group 3	6
Group 4	6
Group 5	5
Group 6	7
Group 7	6
Total	37

The term "stakeholder" is recognised by the evaluation team as “any individual, group or organisation who affects or can be affected by the TCAT programme".

In total we identified 70 individual stakeholders, with many involved in more than one of the key structures of TCAT’s programme.

- TCAT Programme Board (n=24 and 9 involved in one or more other structures)
- TCAT Cancer Experience Panel (n=13),
- Evaluation Advisory Group (n=13 and 3 involved in one or more other structures)
- Members of Regional TCAT Implementation Groups (n=35 with 10 involved in one or more other structures)

We used a pragmatic approach to our sampling, selecting 11 participants that represented the main structures of the TCAT programme. All but two were conducted face to face

Analysis

All data were subjected to thematic analysis. All transcripts were initially listened to and read to check the accuracy of the text. The transcripts were coded using the software, QSR NVIVO and verified independently by two members of the team for consistency and interpretation. As our overall evaluation design adopts a realist and appreciative inquiry approach, there is a deliberate focus on **what works well** and **what is not working so well** to date, and the organisational and contextual factors that are seen to be affecting the programme positively and negatively at this stage.

Findings

The qualitative data provided an important insight into the TCAT programme. Through the interviews with stakeholders and the focus groups with project teams, some common themes emerged, specifically in relation to:

- The meaning of ‘after care’ and ‘transformation’
- The scope of TCAT
- TCAT structures and design
    - Structure
    - Learn and share events in 2014
- Early development and implementation processes
    - Application process
    - Early implementation
    - Partnership working within the programme design
- Partnership working and integration
    - Evidence of Working together on TCAT projects
    - A positive base for progressing integration
- Sustainability of TCAT
- The role of patients and carers in TCAT

The meaning of ‘after care’ and ‘transformation’

A key theme emerged from the scoping of the variety of meanings associated with the term “after care” among stakeholders and projects. Some believe that to ensure comprehensive care after treatment, this ‘care’ has to start at diagnosis.

> *“if we want people to feel supported and enabled afterwards, that has to start earlier” (Project)*

> *“the programme, aftercare is what happens after acute treatment is finished. I really struggle with that, because, I think if you’re going to transform care after treatment is finished……., then you have to start at diagnosis and work through the diagnosis and treatment” (Stakeholder)*

> *“it would probably be open to a few different interpretations because obviously through treatment you need care for that, care through treatment. I suppose what I'm saying is you need it at every stage of the pathway”. (Project)*

Others discussed how patient and professional perceptions and expectations of TCAT were shaped by the use of the term *“after treatment”*. Some had the impression that TCAT projects are about “*adding on*” after the secondary care based part is complete, and not as envisaged, a separate but “*seamless*” part of a person’s cancer journey.

A number of individuals talked about the programme as relating specifically to the “*follow up*” of patients and interpreted TCAT as actions/services/interventions that began for patients on completion of “*active*” treatment. This emphasis also raised issues about the language of TCAT and how this could affect patients, specifically in their understanding of terms such as “*after treatment*” and “*active treatment*”. The chosen title of ‘Care After Treatment’ has impacted differently on the emphasis of local projects.

Some projects talked about their experiences and concerns of how the interpretation of the term ‘after care’ by patients had or could result in them not accessing the TCAT services being developed, as they considered themselves to have not had, or not completed “treatment”.

> *“What I found from some of the phone calls that have been,. Is - there isn't a definition in the public, or out in the wider area of what treatment is. Because I've had a lot of people phoning up saying, oh that doesn't apply to me 'cause I've just had surgery, I've not had chemotherapy, or radiotherapy, or whatever. And it's like, well actually it does, 'cause your surgery was your treatment. And there's been people saying, oh I didn't actually need, you know, I'm just getting monitored. And it's like, well yeah that's still part of your treatment. …..It should be everybody that's had cancer, and never mind what their treatment was.” (Project)*

Some stakeholders and project teams questioned the Programme’s title “*Transforming Care After Treatment*”. Others viewed as unnecessary the additional TCAT ‘strap line’ under the logo now seen on Programme documents – “*Transforming Your Cancer Care*”, where as some consider it to be more applicable to the work they are doing.

> *“the programme is called, after treatment, and we are already … .. trying to shoehorn it to after treatment,... So, you say, well of course absolutely, you would start something sooner to be in place for after treatment, but there's a real kind of misunderstanding about that……. so if it's transforming your cancer care, then that's full pathway work, not after treatment work.” (Stakeholder)*

> *"Calling it, Transforming Your Cancer Care, seems much more appropriate, because they do have cancer and it is care that we're giving. It's just not a sort of defined treatment as people come to expect." (Project)*

In parallel with the meaning of 'after care' and 'transformation' a second key theme identified by the scoping work is that of the actual *'scope'* of the TCAT programme.

The scope of TCAT

A number of stakeholders and projects raised some concerns about the scope of the TCAT programme. Some of their comments are illustrated below. (See Figure 2).

Figure 2: How the scope of TCAT was described

This perception of an unmanageable scope is seen within the context of the breadth of TCAT's aims and the range of components/development priorities to be addressed locally. The initial roll out of the programme via individual local projects has resulted in a wide and diverse set of TCAT projects across Scotland. It is this diversity that appears to have created a lack of clarity among those involved as to the priority aims and objectives of the TCAT programme. The expectations of the TCAT programme overall are as wide and varied as the diverse elements and local emphasis of the individual projects that met the national programme criteria for phase 1. Examples of how individuals spoke about this diversity are given below:

> *"My expectations of TCAT is we end up with a number of models that have been tested and scaled up with the more holistic responses follow up on care after*

> *treatment......just having a better more responsive, more holistic way of following up and managing patients secondly we really need a way of moving patients from secondary care to primary care." (Stakeholder)*

> *"It's more that we want to re-shape how the allocation of resources takes place. But we want to have exemplars, we want to have models. .... It should just be all one system and I think TCAT in lots of areas is proving to be an interesting example of how that kind of thinking and working together can take place".(Stakeholder)*

> *"because we've got this big health and social care integration agenda and here's something that… If it's done well at a project level, building up to a programme level, here's a good example of how this could work and could work in a difficult area". (Stakeholder)*

> *"You've got to think about the long term vision, the bigger vision in what you're doing, you know. So that if we invest in these processes, the hope is that it will impact on every service, you know, and positively"' (Project)*

As the bottom up programme design has sanctioned this diversity and resulting scope it has to be mindful of its implications. The emphasis given to 'transformation' and care *after* treatment, albeit only within the title of the programme, is shaping expectations and perceptions of the programme overall and within local projects. Our scoping has identified that there may be a need for clarity around the priority messages of the TCAT programme. TCAT must work to promote the dual message of having one ultimate destination but many routes to success that are being trialled and tested by the programme.

TCAT structure and design

Structure

We identified that the iterative build-up and variability of approach to design and 'support' capacity has had an impact on the TCAT programme overall and at a local level. Phase 1 projects were agreed in December 2013, in advance of many parts of the governance and support structure being established.

Table 2: Iterative build-up of structure

Pre-launch	JUNE 2013	Nov-13	Dec -14	Jan-14	Apr-14	May-14	Jun-14	Jul-14
TCAT Project Manager & WoSCAN Project Manager		SCAN Project Manager		WoSCAN Clinical Lead	SCAN Clinical Lead	Edinburgh Napier University Appointed	Edinburgh Napier University Evaluation Workshop	Patient Involvement Manager
	TCAT Launched		Phase 1 projects agreed					

An example of this would be the TCAT Clinical Leads and Project Manager, who were formally appointed as late as April 2014. In the North of Scotland these posts remain vacant and evaluation support from Edinburgh Napier University only began in June 2014.

This ‘slow build up’ of the programme structure, with each Cancer Network ‘staffed’ differently and adopting significantly different regional approaches to support the early bidding processes and local project development stages, impacted on support .

Although 2014 saw the slow build-up of the formal structures for local TCAT projects, of note, is that some of the key individuals involved in the overall national and regional governance structure have had a significant and positive influence on the development and implementation of TCAT at a local level.

We identified approximately 12 individuals involved in the TCAT governance structures that also hold key roles within local Phase 1 projects. The proximity of these individual’s to the early design and launch of the programme was clearly beneficial to the individual projects.

> *“I sat on the national programme board, as did x, so we both had insight into what was gonna happen, and how it was all gonna work’ (Project)”*

> *‘”I don't know if other people have been disadvantaged 'cause there maybe isn't as clear communication. I'm not sure, I can't speak for them, 'cause I don't know what their communication channels are like. But I feel that we've benefited from the links that we have” (Project)*

In their localities, these individuals have fostered local commitment and enthusiasm for TCAT within project teams. This may be a result of the bottom up approach.

> *“I think there's definitely a will and an enthusiasm for it. Right from the word go, people have been kind of keen for the bid to go forward, and to be involved in it, from all of our partners really” (Project)*

> *"it's about having a positive attitude because that's what people would say. You've got to have a can do attitude. You have to be positive about things and bring people along that way and I think that's really important. People who are being maybe slightly negative or whatever, it's just slowly working away at that" (Stakeholder)*

We found a high level of commitment and positivity towards TCAT and the added value of being part of this national programme among projects and stakeholders.

> *"I suppose you do feel part of it because you're aware of the work and I think most people still have that common drive as to why they're doing it. So I do feel part of that" (Project)*

> *"You have a hook you've said already with some of your colleagues in terms of a focus, a community of interest in terms of that" (Project)*

> *"but already because we're part of this project its raised the profile" (Project)*

Stakeholders and local projects reported that they feel part of the national TCAT programme and see benefits from this association. The key benefits or added value were described as including:

- Provision of a platform for beginning related partnership work
- Raising the profile of the needs of people living with cancer and care models that could support them
- The availability of money from Macmillan to implement local priorities

Part of the TCAT programme design was the hosting of a number of 'learn and share' events for local projects. These aimed to support those involved in taking forward phase 1 projects and sharing the learning from their development and implementation.

Learn and share events in 2014

The Learn and Share events had mixed benefit for the project teams. A number of the projects viewed these events positively as illustrated by the narrative below:

> *"The first one, where they had people from the survivorship (work in England), who had been there, done that, a couple of years ago, that was really informative'. (Project)*

> *"People want to have time with each other to share experience and understand each other's worlds. So the events that are given a lot of that I think have been quite popular. On the other hand people want to be told. They want to have*

> *cutting edge experience shared with them and lessons from elsewhere. So I think it's quite hard to get a balance between those two things."(Stakeholder)*

> *"And I went to the one in July [June], about evaluation….the part of that that was most helpful was going through the logic model. We sat, and we went through our project, and done it as a logic model, and that was helpful for me to gain better understanding of the project and what was the plan for that. And just to like meet some people and stuff, 'cause like I say, I was brand new to the whole team then." (Project)*

Despite learning and sharing being a top priority of the TCAT programme, not all individuals saw the benefits of this format. One project participant suggested they were perceived as "*eating into time*" for locally focussed development and implementation. The local projects are at different stages and some project teams that were ready to 'go' and deliver their new service, found that they could share their experience but perceived less learning for them. This is illustrated below:

> *"I would say I've had limited learning from that, in terms of our project. Because there was no other project like ours. And we were also a bit ahead at each of the last couple of events.' (Project)"*

> *"They were all different stages and for me it was always about how we actually encouraged the learning and the sharing of that learning across the different projects going forward. So, that for me, was my role was to try and do that, was to try and bring them all together to be able to do that as well as that also being done by the regional group as well."(Stakeholder)*

The mixed benefits of the "learn and share events" were not found to have added significant or equitable value to the programme at this stage. The overall programme design; with dedicated regional input, key TCAT individuals, a local sense of ownership and commitment, engendered by the bottom up approach, are key positive aspects of the programme design and implementation to date. These factors have aided local groups to address and overcome a range of challenges presented by the required application and administration processes.

Early development and implementation processes

Application process

The application process was described as onerous, long and unnecessarily protracted by local projects, even to those that had followed the Macmillan Cancer Support expression of interest previously. A number of specific 'challenges' were identified by all the project teams and are summarised below:

- expressions of interest being changed from the original submission; this included be a reduction in years of the project, reduction in costs/requested budget, or an amalgamation of projects with similar goals or cancer type
- capacity at a regional and local level to produce expressions of interest and Partnership Application documentation (paperwork),
- perception of duplication of communication channels for clear advice,
- concerns among stakeholders that the criteria set for TCAT was not adhered to strongly or consistently for Phase 1 projects,
- clarity as to the parameters of project scale, length of projects,
- ambiguity around local evaluation responsibilities and costs.

Early implementation

Early implementation challenges identified include the continued ‘paperwork’ requirements, local and regional capacity for administration and in some case project management, recruitment delays and for some projects IT issues.

> *“So it seemed to slow to the rate, or the pace, of the slowest project, rather than allowing projects to progress independently if they were further advanced”. (Project)*

The prolonged process was acknowledged by the regional stakeholders, in particular, the application process plus the 6 – 9 month development phase, as consuming most of their job at the expense of other responsibilities they had.

Partnership working and integration

A key aim of TCAT is to initiate and embed an integrated approach to the provision of after care involving health, social care and third sector partners. This section looks at the extent to which the programme to date has enhanced service integration and co-ordination of after care services and support.

We look in more detail at the perceived potential of TCAT in this area, the early evidence of health, social care and third sector organisations working together and provide comment on the actual extent of integration evident at this stage.

Partnership working within the programme design

The scoping work identified an important issue relating to the extent of partnership as envisaged by the programme design.

Among a range of projects and stakeholders there is a level of concern and to some extent ‘unease’ as to the level of engagement and participation to date with the third sector. This was particularly true in relation to the involvement of other cancer charities in Scotland.

> *“But I think we could do better at getting a shared agenda there, so we’re speaking from a third sector platform”. (Stakeholder)*

> *“but it doesn't leave a lot of scope for smaller organisations.” (Project)*

> *“Yes, well, I think it’s important that they (smaller charities)… don’t feel left out and Macmillan are supportive of that. Macmillan have the big carrot of having quite a lot of resources, but the other charities are doing excellent work as well” (stakeholder)*

> *“And, the other charities are not at the table. And, that is just because this is a Macmillan funded project …. but there are a number of the other smaller charities and the tumour specific charities, who’ve got good ideas around transforming care as well” (Stakeholder)*

> *“At the moment, lip service is paid to the other charities”. (Project)*

Evidence of Working together on TCAT projects

Early evidence of early engagement and consultation between many of the project teams and some organisations was found. For example local projects are or will be overseen by representatives of a range of organisations and therefore benefit from multi-disciplinary input.

However, the document review indicates early engagement with ‘Third sector’ organisations and predominately, Maggie’s Cancer Caring Centres, with few if any other local voluntary sector organisations being noted. A number of local projects have consulted and/or are working with cancer specific charities and two local projects had not been in contact with any third sector representatives in preparing their expression of interest.

During our scoping work we made a distinction between working together, (being engaged in processes and having been consulted) and integration/joint service provision. For all but 2 phase 1 projects it is not clear at this stage the exact roles of primary and community based health services, social care and third sector in the *actual delivery* of the new models of care, their responsibilities to people with cancer and their level of influence overall.

A positive base for progressing integration

There is early evidence that TCAT has certainly initiated moves towards partners getting round the table to examine their potential and future role in the after care of people affected by cancer. Stakeholders and local projects see TCAT as providing tangible opportunities to pursue integration and partnership around services for people with cancer and a vehicle to focus on the wider integration agenda.

> *"TCAT structures, if you like, enshrine the importance of partnership. And if somebody's not at the table, that's really noticed and that becomes quite a useful, kind of, shaming factor". (Stakeholder)*

> *"just getting round the table with different teams, has been rewarding as well. Just in terms of making contact, which I suppose is what integration is all about."(Stakeholder)*

> *"I think having TCAT project as a focus has helped us…you know we've already formed some links with social work and…you know we've always had links with Maggie, but develop them all…informal links over the projects, so I think we've already got better relationships with all those people, and more contacts just because we've met over developing the project" (Project)*

Another significant driver of TCAT related integration and partnerships is senior level engagement in local projects. One stakeholder described these individuals as champions;

> *"the champions are great, but you need it at a really senior level". (Stakeholder)*

While others describe this as leadership at strategic level;

> *"And I think there's leadership obviously displayed with the steering group, but it is essential to have commitment at the top". (Project)*

> *"So I think that strategic level adoption of it was crucial". (Stakeholder)*

Other drivers identified by participants to progress partnerships and service integration, at this early stage; were a previous history of joint working, an enhanced understanding of involved partners, their environment and potential roles in relation to TCAT, and the wider engagement work carried out by at least two local projects.

Although the scoping has identified a number of factors that illustrate a positive base from which to progress partnership working and service integration as the programme evolves, a small number of stakeholders reported that they considered the Phase 1 projects not to have very well developed plans or action in relation to integration of services and partnerships.

> *"A tactical and principled decision was taken that phase 1 had to be based on acute settings and secondary care, because clinicians would need to have confidence to let go. I think that was a fundamental mistake. I argued my corner*

> *for that. I thought they should all be required to partner effectively across acute primary care and local authority and third sector" (Stakeholder)*

> *"So because we were so desperate to get bids in, we were a bit, kind of, soft on the partnership legitimacy. So there was a bit of a weakening of the requirement for partnership on the basis of I think trying to get some bids in. And they were good bids. I mean, I've got no doubt that they'll generate good outcomes and services for people" (Stakeholder)*

Sustainability of TCAT

A primary aim of TCAT is to embed a sustainable approach to after care services. The TCAT programme has been designed to ensure the Cancer Networks have a key role in sustainability. Some stakeholders commented upon the scale of this future role and the local and national challenges such work would give rise to:

> *"I would say it's probably 50/50 in terms of whether they think it's an added value to the regional structures. But, at the same time, you can't exclude them from this part of the process and having a say in what they think is workable, sustainable and is spreadable, you can't expect them not to be involved in that and then come along in a year's time and ask them to help spread what's happening at a local level". (Stakeholder)*

> *"from observing how things happen in the NHS, ….spread isn't very easily achieved. I think the people are quite insular and quite protective of what they've done and are not keen to spread it or allow it to be spread". (Stakeholder)*

> *"some of them are going to work well, I'm sure, so how do we scale them up and sustain them given the pressures on the NHS and the lack of money in the system. That's a big challenge." (Stakeholder)*

> *"yes, a region can endorse something, but ultimately for anything to do that's sustainable, and it kind of raises a question then, if money goes to a Board, how do you actually role it out to another Board that didn't get the same money to do it?" (Stakeholder)*

The *overall evaluation* will examine the extent to which the impact of the programme and the work it is funding will be sustainable and to look in detail as to whether or not the programme has been successful in influencing the strategic joint commissioning across the NHS and local authorities to enable sustainability.

As part of the *scoping* undertaken by Edinburgh Napier University, we looked at the projects' plans and asked stakeholders and project about the issue.

The expression of interest documentation for phase 1 doesn't ask prospective projects about potential sustainability. The Macmillan Partnership Application does. It asks:

- How will the projects outputs/outcomes be sustained locally
- Outline what the exit strategy will be
- What is required for the benefits to be sustained?

Some projects highlight the need to demonstrate positive impact first to encourage roll out of services; others refer to their TCAT project as a pilot. Therefore only during the pilot or on completion will issues of embedding it into practice be considered.

One project's expression of interest identifies that sustainability has in part been approached via enhanced and close partnership working and one other project identifies uncertain sustainability as the main risk to the project overall and have already begun discussions with a view to securing longer term funding.

A strong sense of ownership among the project teams was found which as the projects develop will enhance the potential for sustainability. In addition at this very early stage of TCAT another key aspect related to sustainability, is whether the programme has been successful at influencing attitudes, behaviours and priorities related to after care.

During the focus groups a number of participants described early evidence of changing behaviours and attitudes to after care and partnership working. This was reflected in both their own professional knowledge and practice, and witnessing the professional behaviours of others.

> *"the project so far has just made us really aware of what's out there, and how we can help mainstream services, …. that will be much more, I think, beneficial for them (patients).., because there's so much out there' (Project)*
>
> *'"there's probably been a little bit of early impact working with social care,…… …I think in terms of their understanding …….there were sort of quite a few light bulb moments." (Project)*
>
> *"I think probably what it's done without realising it, because we haven't yet promoted it or talked about it because we've nothing yet to promote per se, but I think what's really good is that within our own department, whilst there may be a core of us that have been interested in the survivorship agenda generally, I think we're beginning to see some small step changes of interests amongst clinicians generally and recognition of the importance of survival.'"(Project)*

The Regional Stakeholders also expressed their awareness of TCAT having an impact on professional attitudes and behaviours.

> *"I think people are beginning to see it. I can see a difference between when I first came out to do the TCAT work because I believe in it. I see a difference from then to now. I see people are more talking about it. I can see with my own peer group……We've still got a long way to go, but this is...I mean, when you think how long it's taken them to re-write a chapter on other conditions, we're not going to do big wahoos overnight." (Stakeholder)*

Finally also related to sustainability is the aim of TCAT to increase skills and knowledge among professionals locally to improve after care services. The extent to which TCAT has contributed to increasing skill and knowledge to improve after care has not been addressed in our scoping work. It remains a key evaluation question the Next Steps for the national evaluation section sets out our planned approach.

The role of patients and carers in TCAT

Inclusion and resulting influence of the patient voice is a key TCAT strategic aim and was viewed as important at a national, regional and local level.

> *"What was important to me was to make sure that we avoided that it wasn't a token gesture, that it did have, …….. some degree of weight in terms of the influence it had on the programme going forward, and making sure …….. that projects understood that as well"' (Stakeholder)*

Several local projects and stakeholders spoke about the patient voice and that it should not be "*tokenistic*" while also raising concerns that the nature of this population is a vulnerable group i.e. patients can become ill and step back from the group in which they are involved.

The TCAT programme took 12 months to establish a TCAT Cancer Experience Panel. At present there are 13 individuals with a lived experience of cancer that form part of this group. It is in its infancy and still establishing their role and identity. Nationally there is awareness that the TCAT Cancer Experience Panel could represent all populations of service users, which at times is hard to configure. Stakeholders and projects acknowledge that support and training is essential for individuals involved in their processes but also recognise the inherent challenges.

> *"But I think I'm mindful that I need to be making sure that they feel okay and that they feel supported and that they understand that there is other people like them working in similar ways on different projects, and is there any mileage in how we support them getting together or linking it in with the National Patient Group." (Stakeholder)*

> *"there's every danger that that person will be quite isolated and potentially need a bit of support and so we're hoping to set ourselves up to be able to provide that*

> *and that may be through individual links with specific members on the TCAT cancer experience panel” (Stakeholder)*

There is patient representation on Regional TCAT Implementation Groups and on a small number of local project groups. Two out or seven projects had a patient representative present during the focus group discussion. However a number of projects described different ways in which they have incorporated the patient voice into their project design.

> *“Because the patient focus groups, obviously they feed back and engagement in terms of…well, some of them are early, that they're feeding into the process about the kind of service or intervention and others will be reflecting on their experience of the intervention.” (Stakeholder)*

> *“that says so much about what this project is about, and the importance of patient involvement. You know, it totally changed the dynamic of the regional group, in what we're doing, and how that's cascading down, you know. And we're now going to sort of embark on recruitment of more people from the boards, because people, just because they're in the acute phase of their illness, some of them have had to sort of step back from it. But again, as I say, I just think it's fantastic that there is true patient involvement in the project.” (Project)*

The work to date to incorporate the patient voice has been slow to come on stream within the national structure, thereby limiting its influence during the early phase 1 stages. Overall the role of patients and carers within the TCAT programme at all levels requires clarification and prioritisation.

Conclusion

The qualitative data has provided some early insights into the impact, processes and outcomes of the TCAT programme. As our overall evaluation design adopts a realist and appreciative inquiry approach, there is a deliberate focus on **what works well** and **what is not working so well** to date, and Table 3 summarises the organisational and contextual factors that were identified from the qualitative findings affecting the programme positively and negatively at this stage.

Table 3: Summary of scoping findings

What is working well?	What is not working so well?
Opportunities that come from diversity of local projects and bottom up approach	Clarity around the key aims of overall programme at all levels
Local ownership of projects	Impact of different meanings and emphasis placed on terms ‘after care’ and ‘transformation
Establishment of a support structure	Scale of expectations and anticipated outcomes
Potential to learn and share	Current approach to ‘learn and share’ components of TCAT
Local individuals being linked to TCAT governance structures	Slow build up and variability of programme structures at regional level
TCAT Champions	Administration processes relating to application and early implementation
Established positive base for future integration and partnership	Actual implementation of integration and partnership working
Capitalising on history of joint working at a local level in some areas	Capacity at all levels of TCAT programme
Commitment to ensuring a key influential role for patients and carers	Vulnerability of patient voice within TCAT and limited / stalled action to date
Senior level engagement in TCAT in some areas	Less focus upon risk stratified care than on other TCAT development priorities
Added value from being part of a national programme	Limited plans for enhancing potential for sustainability

SECTION FOUR: DOCUMENT REVIEW

Introduction

The design of the TCAT programme is such that the delivery and achievement of much of its success is dependent upon the funded local interventions and models of care. As the answers to many of the evaluation questions are not available as yet, this scoping provides the required programme overview and profiling of local projects. As part of this process Edinburgh Napier University reviewed the phase one project documents such as initial bids, minutes and partnership agreements.

Profile of phase 1 projects

The size, activities and timelines of the phase 1 projects varies considerably and the diversity of projects became a predominant theme of our scoping.

All phase 1 projects are initiated in the hospital setting and focused on one or more specific cancer types; some are making multiple changes in current working practices and others small developments to test new approaches and models.

Projects were mapped against the “Essential Service Delivery Developments” set out in the TCAT bidding documents. These elements of assessment and care planning were presented to potential local projects as “crucial to the success of the programme. These include:

1. Holistic needs assessment tools
2. End of treatment summaries
3. Cancer care review
4. Health & wellbeing events
5. Risk Stratification

Of importance to a national programme is the overall timeframe within which impact can be seen. The first phase 1 project began in October 2014 and the latest completion date for phase 1 is at present estimated to be March 2017.

Holistic needs assessment

All the projects are using an assessment tool to gather data about the needs of those affected by cancer. Three projects have modified existing templates used in their service, one is using the SPARC (Sheffield Profile for Assessment and Referral for Care) and the remaining seven are using either a paper or e-version of the concerns checklist/Holistic needs assessment tool. This provides all the projects an opportunity to capture the needs of their population and some of these elements can be drawn together to inform the overall evaluation.

End of treatment summaries

Nine out the ten projects are introducing an end of treatment summary. Two of these will use KIS (Knowledge Information Systems), a system currently in use within their service.

End of treatment review points

Six phase 1 projects aim to incorporate End of Treatment Review points within their local TCAT project. For most this takes the form of a follow up appointment at an agreed period after treatment. (For one project this is 4 – 6 weeks, for another 6 – 12 weeks). Two set out that these review points will not take place in a secondary care setting (stating community hospital and primary care as the location for review point).

Four phase 1 projects intend to develop new TCAT health and wellbeing events. Our scoping work has identified that they are diverse in scale, scope and timing of provision. Related to this 5 local projects plan to ‘map’ the relevant services in their area to inform and improve referral and signposting practice on completion of HNA/ end of treatment review. TCAT identified access to community based resources as a key component of follow up care and this will be an area for further enquiry post project implementation.

Cancer care review

Only one phase 1 project will offer a more formal cancer care review within primary care.

Risk stratified follow up care

A development priority for TCAT is the provision of risk stratified follow-up care. For TCAT there are seen to be 5 components of such follow up. These are:

1. A clear assessment of needs as part of an integrated care pathway
2. A process for monitoring person affected by cancer
3. A co-ordinated, integrated rehabilitation service providing an education and support plan
4. A rapid and responsive person-led access back to acute care
5. Access to community based resources.

The document review found that a risk stratified approach was identified and described as part of the planned intervention of five phase 1 projects. Similar to the concerns expressed in relation to the development of integrated services, a small number of stakeholders questioned the extent to which this key component of the recovery package had been addressed by phase 1 projects.

Table 4 illustrates how these elements have been incorporated within Phase 1.

Table 4: Essential service delivery developments of phase 1 projects

Network	Host	Cancer Type	Type of Assessment Tool	End of Treatment Summary	End of Treatment Review Points	Wellbeing Events	Cancer Care Review (in Primary Care)	Project Lead
N	NHS Tayside	Pelvic, Head & Neck	eHNA	yes		yes		Nurse consultant
SCAN	NHS Dumfries & Galloway	Breast	HNA	KIS			yes	GP
	NHS Lothian	Prostate, Breast, Endometrial/Cervical, Anal/Rectal, Lung	HNA	yes	yes			Nurse consultant and hospital consultant
	NHS Borders	All cancer groups	HNA	yes	yes	yes		Nurse consultant
	NHS Fife	Skin	HNA /eHNA	yes	yes	yes		Hospital Consultant
	NHS Fife	Lung	Fife MDT doc	KIS				Nurse Consultant
WOSCAN	NHS Ayrshire & Arran	Breast	eHNA	yes	yes	yes		Nurse Consultant
	NHS Greater Glasgow & Clyde	Breast	Developing new qn.		yes			Hospital Consultant
	NHS Forth Valley	Prostate	HNA	yes	yes			Hospital Consultant
	NHS Lanarkshire	Lung	SPARC	yes				Nurse Consultant

Economic evaluation

One of the goals of the TCAT programme is to ensure changes in service delivery are cost effective and value for money. We carried out an economic impact review aimed to address two main issues identified in the evaluation objectives:

- to assess the ability and extent of the TCAT programme to generate more cost effective solutions in cancer
- to assess the economic impact of improved outcomes for people with cancer.

Each project's expression of interest application was reviewed using a standardised proforma to help identify economic evaluation potential. In particular projects were evaluated for their interventions, opportunities for control groups/comparisons and relevant outcome measures such as quality of life measures using validated tools (e.g. EQ-5D or SF-36), and the amount of support required to generate these data.

Few of the projects have measurements in place to gather data to inform this. There is a wide range of economic evaluation techniques available which can be used to explore practice changes. The diversity of projects not only for this phase but for future phases of TCAT mean that several of these approaches would be appropriate and this choice should be guided by individual project designs. Using a standardised pro forma to identify any economic evaluation potential the initial review resulted in three groups (See Figure 3). However the decisions relating to whether economic evaluation is possible and if so, which methodologies will be used have to be guided by the individual projects themselves.

Figure 3: Phase 1 projects and potential health economic analysis

Group 1	Group 2	Group 3
NHS Lothian	NHS Borders	NHS Fife (Lung)
Greater Glasgow & Clyde	NHS Forth Valley	NHS Ayrshire & Arran
NHS Tayside		NHS Lanarkshire
NHS Dumfries & Galloway		
NHS Fife (skin)		

Group One: The nature of the intervention does not lend itself to gathering health economic data, for example in NHS Tayside where no collection of control data is planned. Although NHS Greater Glasgow & Clyde indicate they will measure costs, the project outcomes are looking to improve the experience of health care post TCAT intervention. The costing of a good health care experience (i.e attributing the costs of a "good" experience vs. a "bad" experience) is highly complex and is at the experimental stages of health economic methodologies. This project therefore would not be suitable for inclusion in the economic impact analysis in this body of work.

Group Two: These project teams have considered economic evaluation but are not collecting outcome measures which would be useable in economic evaluation. NHS Borders are planning cost description and workforce analysis. NHS Forth Valley were keen to consider economic evaluation and had costed for an external team to undertake this aspect of their evaluation. As such, the team are not gathering the required data and would require intensive support beyond the scope of the Edinburgh Napier University team's resources to set this up.

Group Three: This final group includes three projects that offer potential for economic impact analysis. These projects are planning to collect relevant data and with some additional support from the health economist it is anticipated they could provide meaningful economic information to address questions about impact and inform service delivery.

NHS Ayrshire and Arran, NHS Lanarkshire

To date, the Edinburgh Napier University team have identified the potential to gather economic evaluation and meetings are to be arranged in January 2015 to begin planning how the team can best support the projects.

NHS Fife Lung Cancer

To date, the Edinburgh Napier University health economist has met and agreed a programme of work to aid the economic evaluation potential of the NHS Fife Lung Cancer project. In discussion with the project team, it was felt that using decision trees to map the potential patient pathways prior to (i.e. Best Supportive Care) and post the TCAT intervention was the most useful and appropriate method. Decision analytical modelling using decision trees provides a framework for the mapping of processes and subsequent synthesis of data from all relevant sources to aid decision making[19].

The decision trees will be built by the Edinburgh Napier University health economist in collaboration with the project team to ensure relevance and accuracy. The project team will then test these trees by inputting routine, observational data gathered from clinical audit. Costings for each pathway will then be formulated with the project team and inputted into the decision trees. This will provide information on the probability of each patient outcome identified in the decision tree. Additionally, inputting cost will provide information of the costs of each of these pathways. Costs will be calculated from a third party payer (NHS) perspective. Comparing the costs and outcomes of the decision tree documenting pre TCAT care and post TCAT care will inform how the project has impacted on these outcome measures and can be used to inform the potential cost benefit of the project.

An additional tree will be built to demonstrate the potential patient pathways under conditions whereby Best Supportive Care is delayed or absent. Limited availability of observational data to facilitate the calculation of probabilities for this tree precludes a functional model. However, it is anticipated that the mapping will enable formal documentation of a process which the project team consider complex.

These projects will become form part of our Case Study approach within the overall evaluation. It is hoped there will be 2-3 projects in Phase 2 that can also form part of this group. Any other work would require additional funding. We will apply the same review process of selection for phase 2 and phase 3 projects.

SECTION FIVE: EDINBURGH NAPIER UNIVERSITY SUPPORT

One of the key aspects of Edinburgh Napier University's *overall programme* evaluation is to '*support the self-evaluation of the projects to enable them to provide robust and credible evidence.'* This was undertaken as a parallel activity to our scoping but has also provided data for the initial findings.

Edinburgh Napier University approached our evaluation support role a number of ways.

- Facilitation of an evaluation workshop in June 2014
- Establishment of a support/advice mechanism with named point of contact within the evaluation team for each local project
- Face to face meetings with projects to understand the proposed local evaluation methods and approaches
- Establishment of an on-line Community of Practice site

Evaluation workshop – Glasgow 20th June 2014

One of the key outputs for the Edinburgh Napier University team was to facilitate a 'Learn and Share' event. The Edinburgh Napier University team presented the overall evaluation methodology and framework. Ten phase 1 projects were represented at this event. Local team members worked together to produce a logic model with the support of an Edinburgh Napier University facilitator. Teams were directed to focus upon their client population, activities delivered, data collection tools and short to long-term outcomes.

Following the workshop and with the consent of the teams, a number of Logic Models (n=4) have been placed on the online community of practice site.

Tailored Support

Advice and support has been provided face to face and via email. Edinburgh Napier University met 8 out of the 11 phase 1 projects. In addition to during the evaluation workshop and introductory scoping meetings (see Table 5).

Table 5: Method of evaluation advice and support to Phase 1 projects

Host	Additional Meetings	Workshop Attendance	Telephone	Email
NHS Tayside		√		
NHS Dumfries & Galloway		√		
NHS Lothian		√		
NHS Borders		√	√	√
NHS Fife (skin)	√	√		√
NHS Fife (lung)	√	√		√
NHS Ayrshire & Arran		√		√
NHS Greater Glasgow & Clyde		√	√	
NHS Forth Valley		√		
NHS Lanarkshire	√*	√	√	

*Planned for February 2015

In addition, Karen Campbell (co-Lead for TCAT) provided evaluation advice and support to a number of Phase 2 projects (see Table 6).

Table 6: Evaluation advice and support to potential Phase 2 projects

Host	Face to Face	Workshop Attendance	Telephone	Review of Bids
Edinburgh Council Event	Presentation	√		
North Lanarkshire			√	√
North Lanarkshire(council)			√	
West Lothian			√	
NHS Lothian			√	√
Mid Lothian	√			
NHS Greater Glasgow and Clyde			√	√

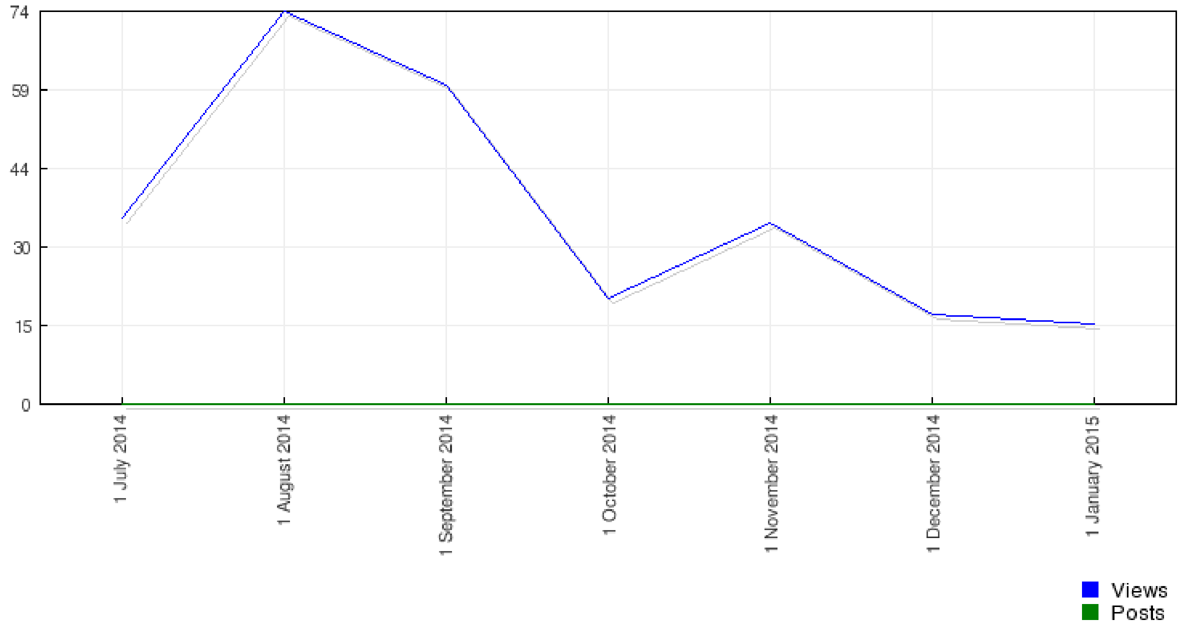
Online Community of Practice

The online community of practice site formed an important aspect or our local evaluation support in our initial proposal.

The community of practice site is a single point of contact across Scotland for resources, information, general queries and the sharing of learning and best practice. Within the site, a forum to ask questions was set up and is supported by the Edinburgh Napier University team. Such a forum allows us to gauge what is working well, where additional support is required and how processes can be adapted to improve support and add value. The online environment promotes an inclusive approach irrespective of location and aims to foster collaboration between local projects. The community of practice affords us the ability to respond quickly to queries and organise face-to-face support as appropriate. As the projects move to the implementation phase it can promote the sharing of good practices and processes between individual project teams. The site is password protected and the TCAT Programme lead has provided access to all of the individuals identified as working on the 11 projects. This site was developed and populated with resources prior to the initial workshop and further activities are planned to maximise its impact over the duration of the programme (see Section Six).

Figure 4 illustrates the level of activity on the online community since July 2014. The level of 'views' fluctuated and were seen to increase at key support stages such as following an introductory meeting. To date there have been no 'posts' by local projects on the community of practice site.

Figure 4: Activity levels on the Online Community of Practice



Conclusion

Based on these findings the Edinburgh Napier University team would propose that the learning and sharing should be specific and directly linked to the aims of the TCAT programme, encourage a celebration of the work being achieved to date and keep a thread running through the event about evaluation with expert speakers. Edinburgh Napier University would also suggest that technology could act as a conduit, not to replace learn and share events, but to enhance the learning from each other and experts in the field.

SECTION SIX: LESSONS LEARNED

Edinburgh Napier University recognise that a considerable amount of work had been undertaken within project teams and throughout the governance structures prior to our involvement. Understanding the complexity of the programme has not been without some challenges and therefore it is hoped that our reflections on what is working well, what is not working so well and lessons that can be learned to date, will inform this evolving programme.

What is working well?

Ownership of projects: There is a strong sense of ownership among the project teams and this is very important. Many individuals have fully committed to this process and invested time and energy to drive it forward.

Integration and partnership: Since the inception of the TCAT programme and as it has progressed, changes in the integration of health and social care is occurring as a parallel activity.

With a large programme such as TCAT, delivered across Scotland, by a range of organisations in health and social care, integration and partnership can be slow to develop. However there are many small changes that have been observed by Edinburgh Napier University within project teams and across networks and regions that demonstrates early success in this area. Individual projects are rightly focused on getting their own changes in place rather than how this joins together within the wider overall programmes. It is important as projects begin their implementation that they reflect on these so they can be captured in their reporting.

What is not working so well?

Keep the messages simple: TCAT has to balance between reaching the people with cancer it seeks to help and the health and social care professionals whose ways of working are changing.

TCAT is a large scale, complex, evolving programme and it is important to consider the language used and the messages relayed. In the document review this came up on a number of occasions. In addition, findings from the focus groups suggest some patients and staff are not always clear about the terms “after care” and “treatment” “follow-up”. Patterns and frequency of follow-up has also changed in the acute sector since TCAT began and many more cancer patients are discharged at the end of initial treatment management. It is timely as the projects begin their implementation to clarify terms and maximise the impact of the programme across Scotland.

Health economics: One of the goals of the TCAT programme is to ensure changes in service delivery are cost effective and value for money. This aspect is perhaps a challenge for the TCAT programme evaluation moving forward. Very few of the projects have measurements in place to gather data to inform this. If projects in the future are required to demonstrate cost effectiveness it is essential that relevant health economic expertise is available from the project planning stage and individual projects have access to support from a health economist not only to complete funding applications but also to carry out data collection, analysis and individual project evaluations.

There is a wide range of economic evaluation techniques available which can be used to explore practice changes. The diversity of projects not only for this phase but for future phases of TCAT mean that several of these approaches would be appropriate and this choice should be guided by individual project designs. Therefore it is not theoretically sound to adopt a one size fits all approach to economic evaluation.

Lessons learned

Making it happen: Project teams have demonstrated a strong commitment to driving forward changes in the way they work. As projects move to the next stage and engage with patients/clients in these new ways of working, it is important they acknowledge the processes to date and learning from some of the challenges that emerged from the application, partnership agreements, capacity and future reporting processes. This is an evaluation risk as it appears to be causing delays particularly in relation to gathering; inputting and collating data moving forward.

Increasing involvement: There is still work to be done to further clarify the role of the TCAT Cancer Experience Panel and specifically our engagement as evaluators. Members of this group have the potential to act as critical friends to individual projects, especially highlighting areas that could be improved. They can share valuable knowledge and expertise. However people can understand involvement differently depending on their previous experiences, local context and focus. The key to the programme is making the voice of people with cancer visible in the decision making processes of the individual projects. This is not to be prescriptive, rather to ensure consistency but also to acknowledge the vulnerability of this group. Where individual projects have good involvement, exemplars should be shared across the programme.

Be realistic around timeframes: The programme has clearly defined timelines and is also evolving. Many of those interviewed felt timelines were a challenge, partly due to; limited understanding of the TCAT vision, no knowledge of other work undertaken by the Macmillan Survivorship Programme and changing care and the application processes. It is important that phase 2 is aware of intelligence gathered to data from other flagship programme. Sharing the experiences from projects in Phase 1 will be helpful to the Phase 2 projects.

Looking inward and outward: Although it has been necessary to focus energy towards how things should develop within local projects, it is also important to have the foresight to have a message that’s going out which will reinforce and acknowledge the work that people are doing as part of the wider TCAT programme.

Managing expectations: There are a number of expectations of individual projects, stakeholders and the evaluators. Re-visiting the original objectives in light of the scoping work may be timely as the programme moves into Phase 2. The individual projects are all working towards the same criteria and it is apparent at this stage that not all of these criteria will be achievable. It is the uniqueness of the Scottish Programme that has encouraged different projects to reflect the local needs of the population but it also challenging for the individual projects. It is important that the overarching aims of the TCAT programme helps keep everyone focused on the overall vision

Balancing competing demands: The connectivity between services is often well established and changes, however minor, can create ripples that impact beyond the initial plan. It is these unintended consequences of change that can create frustration and increase workload among individuals working on or supporting TCAT projects. Capturing these small but crucial elements is important to articulate in the overall National evaluation. It recognises the hard work and determination the individuals have invested to improve services for people with cancer.

SECTION SEVEN: NATIONAL EVALUATION – NEXT STEPS AND RECOMMENDATIONS

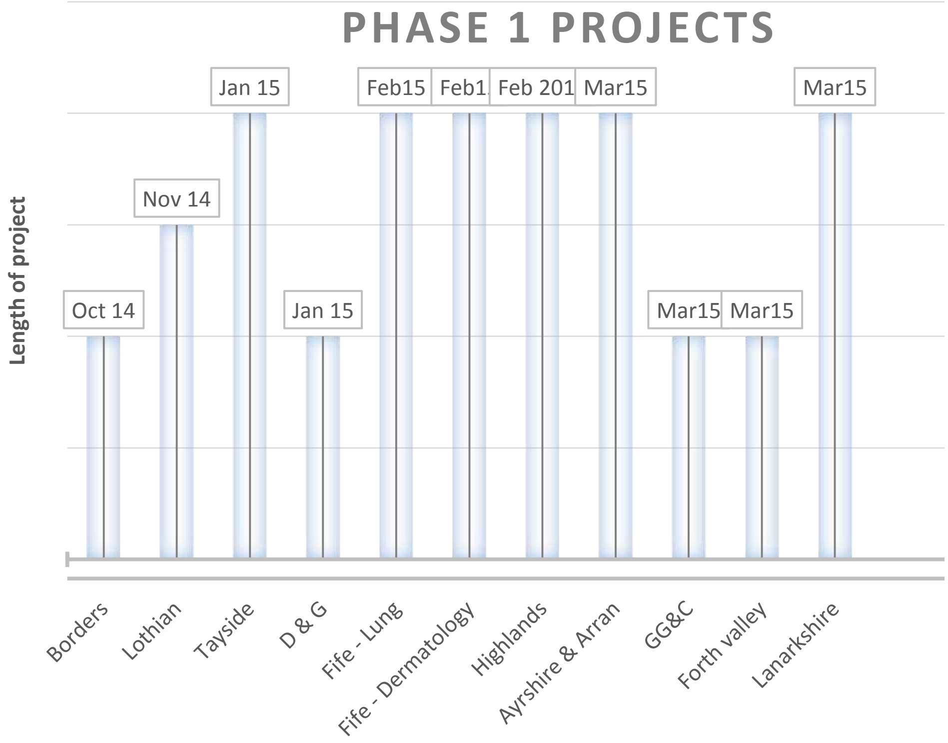
Introduction

The next steps and recommendations from Edinburgh Napier University to take forward the overall programme evaluation are based on the data gathered from all the strands of the scoping work. The scoping work has provided Edinburgh Napier University with an opportunity to provide the Programme Board with an overview of the TCAT programme the issues arising in relation to how to evaluate it.

Timing of data capture

Following the scoping work it is evident that projects are only starting to implement their new intervention/services, affecting when these findings will emerge. Table 9 provides an overview of the 11 projects in Phase 1 and our understanding of the length of the projects (1 or 2 years) and the date they have or intend to move to implementation and delivery. This has provided an opportunity to project when different data streams will be reported and inform the programme evaluation. Once we know all the projects have started, Edinburgh Napier University can project when data should be available for 2015/16 reporting and inclusion into the overall evaluation.

Table 7: Length of Phase 1 projects



Minimum core datasets

Edinburgh Napier University have been working on a minimum core dataset that all projects would use irrespective of setting: Secondary Care, Primary Care, Local Authority or technology. It has been discussed with the Advisory Group and the Macmillan Programme lead and has received a positive response. This is presented as Appendix 3 and its purpose is to gain:

- An overview of the demographics of the patients/clients/users across the whole programme in Scotland
- A record of the key elements used to engage and inform the patients/clients and users with the new intervention/service
- A record of the outputs associated with the completion of the HNA or other assessment tools

It has been apparent in our discussions with projects to date that this core dataset aligns well with what many are intending to do. However, Edinburgh Napier University also recognise that individual projects may want to gather additional data relevant to their particular population, and which informs their own reporting. It will be tested with a few projects on a sample of patients before it is widely rolled out.

Edinburgh Napier University anticipate Projects inputting the minimum core data and transfer this anonymised data to Edinburgh Napier University for analysis in an excel format (a template will be available). We would run the analysis and provide the output back to the project team to use as they wish. Providing a Scotland wide perspective about characteristics of the population engaging with TCAT will be invaluable. Edinburgh Napier University would like to do this on a regular basis and suggest 3 monthly periods. As projects start, Edinburgh Napier University will test this process for, and work with them, to ensure any early difficulties are resolved.

Early discussions are underway to see how the HNA or other tools can be linked. Edinburgh Napier University have sought advice from NHS Lothian ethics Scientific Advisor and will not require NHS ethical review. This does not negate our responsibility to inform all Health Boards and Local Authorities – this process is on-going.

Online survey of stakeholders

Edinburgh Napier University identified a large number of stakeholders. Their roles and responsibilities for the implementation and delivery of the TCAT programme varied. Edinburgh Napier University would like to explore this further through the development of an online survey. This would capture experiences and views over time and can be used at different time points throughout the programme. The survey will be informed by the interview data gathered in the scoping work and the questions in Appendix 3.

Qualitative data

Edinburgh Napier University always intended to use a longitudinal approach to the work with the project teams. This is particularly important as it will capture changes in views, experiences and knowledge as they begin the delivery of the new service/intervention. Edinburgh Napier University plan to repeat the focus groups with the phase 1 teams towards the end of their projects. It is also our intention to sample a number of Phase 2 projects.

Generic patient questions

Based on the scoping work it is unclear how projects will gather data to understand how their project and therefore the overall programme can improve the outcomes and experiences of after care for people affected by cancer. Some projects intend to undertake qualitative interviews to explore this and a few are using questionnaires. Most of the projects are using a HNA or other assessment tool to understand the needs of their population. It will be important to know the outcome for the individual living with cancer Edinburgh Napier University would suggest a simple one page questionnaire could be used to understand whether the intervention increased confidence, skills and knowledge and experience. Edinburgh Napier University would suggest a few simple questions. We feel is important to have feedback from the TCAT Cancer Experience Panel before a document is widely circulated.

Economic evaluation

Based on our assessment in section 4 and resources available to us, we intend to focus on supporting the Phase 1 projects identified. It is hoped there will be 2-3 projects in Phase 2 that can also form part of this group. Any other work would require additional investment.

Descriptive workload activity analysis

A number of new posts have emerged from the funding provided by Macmillan Cancer Support. Our initial assessment, based on the information available, is that few of these posts in Phase 1 are clinical posts, directly delivering the new service/intervention. Edinburgh Napier University would like to undertake a workload activity analysis 3-6 months after each project starts to re-visit this and provide some descriptive costings. The findings would inform a number of questions associated with the overall programme design, for example sustainability and the increased skills and knowledge among the workforce.

Phase 2 projects

Edinburgh Napier University intend to scope the Phase 2 projects using the same methods as used for Phase 1, albeit with a few refinements based on our own learning through this process.

Case studies

A case study approach remains Edinburgh Napier University's preferred approach. This affords the opportunity to focus on specific situations such as integration and partnership, patient voice or population characteristics, key questions of the TCAT programme. The Cancer Networks form a natural "case" as they have responsibilities for the delivery of cancer services to their defined populations but within these it is anticipated illustrative case studies will be conducted, e.g. with a focus on partnership working. The scoping work highlighted where linking of the data could occur and therefore the proposed data collection methods have been chosen to support this.

The provision of evaluation support by Edinburgh Napier University

Edinburgh Napier University have outlined our support mechanisms and this will be refined further as the Phase 2 projects join the programme. We have scoped the range of evaluation methods intended to be used by the Phase 1 projects and will repeat this process to inform our work.

The size and scale of the programme has some unique challenges for the evaluators in terms of support, particularly individual support and we have approached this to date in a pragmatic way. Providing another evaluation day for the Phase 1 projects either regionally or nationally may be useful.

Based on these findings the Edinburgh Napier University team would propose that the learning and sharing should be specific and directly linked to the aims of the TCAT programme, encourage a celebration of the work being achieved to date and keep a thread running through the event about evaluation with expert speakers. Edinburgh Napier University would also suggest that technology could act as a conduit, not to replace learn and share events, but to enhance the learning from each other and experts in the field.

Conclusion

The scoping work has provided Edinburgh Napier University with an opportunity to provide the Programme Board with an overview of our understanding of the TCAT programme and future opportunities to evaluate it. Based on this work Edinburgh Napier University anticipate a number of work streams throughout 2015. These would include:

- Qualitative data gathering from phase 1 and phase 2 projects
- Continuing and developing our support structures for all the projects
- Document review for phase 2 projects
- Gathering core minimum data from all the projects
- Building the case studies

A more detailed work plan will be discussed with the Evaluation Advisory Board.

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APPENDIX ONE: Evaluation Questions

Impact

1. To what extent has the programme improved outcomes and experiences of after care for people affected by cancer?
2. To what extent has the programme enhanced service integration and coordination of after care services and support?
3. To what extent has the programme been successful in increasing skills and knowledge among professionals locally to improve after care services for people affected by cancer?
4. To what extent has the programme been successful at influencing attitudes, behaviours and priorities related to after care locally, regionally and nationally?
5. To what extent has there been increased service user involvement and patient voice, and how has this influenced the design of the programme and projects?
6. To what extent will the impact of the programme and the work it is funding be sustainable in the longer term? Specifically, has the programme been successful in influencing the strategic joint commissioning across the NHS and local authorities to enable sustainability?
7. What has been the added value and impact of Macmillan's role in the TCAT programme?

Economic

8. To what extent does the programme provide more cost effective solutions and a more appropriate use of resources than current practice? Specifically, have the approaches tested through the programme led to:
    a. a reduction in length of stay and inappropriate planned/unplanned and emergency admissions, through increased self-management of cancer and related side-effects and consequences of treatment
    b. more efficient use of workforce resources, with specialist roles focusing on more complex/high level need cases and generalists supporting lower level risk/needs
    c. improved outcomes for people affected by cancer

Process

9. What have been the benefits and drawback of the programme design, including working with the regional networks and the phasing of the project funding?
10. In what ways have projects implemented the various interventions to suit their local context and circumstances, and what benefits and challenges have they experienced in doing so?
11. What are the key contextual and organisational factors that have enabled the success of the programme?
12. What are the key challenges in the delivery of the programme at a local, regional and national level and how and to what extent have they been overcome?

13. How well have the partners worked together to deliver the programme, and what could have been done differently?
14. What are the key lessons learnt and recommendations for the TCAT programme and wider stakeholders?

APPENDIX TWO: PROFILES OF 10 PHASE 1 PROJECTS

Project Title	Forth Valley Phase 1
Cancer Type(s)	Prostate
Project Lead	Consultant Urologist
Intervention/New Service	• Restructure the follow up of prostate cancer from hospital to a community/nurse led model • Introduce the use of HNA and end of treatment summaries
Key Outcomes	• Improved patient experience • Patients seen closer to home • Improved ability to self-manage • Improved communication with patients and between teams • Increased use of voluntary sector and social services as appropriate
Changes in Practice (examples)	• Restructure the follow-up of prostate cancer from the hospital to a community/nurse led model for men with stable disease. • Offer one free month to patients for the rehabilitation/exercise programme • Mapping of services to develop a directory that can be given to patients
Starting Date	March 2015
Completion Date	1 year project

Project Title	Fife Melanoma Phase 1
Cancer Type(s)	Melanoma
Project Lead	Consultant Dermatologist
Intervention/New Service	• Introduce end of treatment summaries at time of discharge to primary care • Patients complete a HNA and this is reviewed by skin cancer link nurses • Patient led access back to secondary care • Patient self-management groups
Key Outcomes	• Reduction in number of consultant visits and allowing more new patients to be seen • Direct access back to consultant/secondary care
Changes in Practice (examples)	• Alternate 4 monthly follow-up appointment between the consultant and Dermatology ‘skin cancer link nurse’, use the HNA and send out in advance • Utilise plastic surgery ‘skin cancer link nurse’ • Set up patient self-management groups: 4 per year at each site • GP can refer directly to dermatology skin cancer link nurse • Undertake a scoping exercise to determine community resources
Starting Date	February 2014
Completion Date	2 year project

Project Title	Greater Glasgow and Clyde Phase 1
Cancer Type(s)	Breast
Project Lead	Consultant Surgeon, Clinical Lead for Breast Services
Intervention/New Service	• Implement, test and evaluate a questionnaire designed to “under pin a self-management model” • Transition from acute care at end of active treatment to a community setting, via supported self-management • Signpost patients/carers to available resources/services
Key Outcomes	• Improved and increased level of appropriate support that replaces contacts with secondary care
Changes in Practice (examples)	• Development of a new questionnaire to identify clinical, social, financial and psychological issues
Starting Date	March 2015
Completion Date	1 year project

Project Title	Lanarkshire Phase 1
Cancer Type(s)	Lung
Project Lead	Nurse Consultant
Intervention/New Service	• Introduce end of treatment summaries, end of treatment reviews and the e-patient reported outcome measure (SPARC: Sheffield Profile for Assessment and Referral for Care)
Key Outcomes	• Development and support of an integrated model of care • Innovative and transformative model of follow-up care utilising technology that can be transferred for use in other patient groups • Test and evaluate the tools used • Patient, centred model of care responsive to patient needs – covers all domain of need – move away from medical model • Support transitions within current healthcare – local settings
Changes in Practice (examples)	• Nurse led reviews • PROM sent out monthly for 6 months to patients and reviewed by CNS
Starting Date	March 2015
Completion Date	1 year project

Project Title	Lothian Phase 1
Cancer Type(s)	Lung, Rectal/Anal, Breast, Endometrial/Cervical, Prostate
Project Lead	Nurse Consultant in Cancer AND Consultant Urological Surgeon
Intervention/New Service	• HNA will be completed by specialist nurse or consultant 6 – 12 weeks after treatment at a new end of treatment recovery clinic • Introduce End of treatment summaries
Key Outcomes	• to develop social care integration pathways and provision of signposting to essential services • Identifying needs and concerns early, anticipating potential issues, and improving quality of patient recovery. • Additionally, in prostate cancer – improvement in timely access to support the already known common consequences of prostate cancer surgery (incontinence and erectile dysfunction) in response to patient feedback. • Improved quality of patient recovery for all tumour groups. • A systematic and equitable approach to supporting end-of-treatment recovery that can be embedded in to routine practice across all cancer groups. • Improved communication and transition for patients between secondary and primary care at end-of-treatment. • Transformation towards health and social care integration. • A possible reduction in hospital/primary care contacts made by patients over the 6-month post-treatment period.
Changes in Practice (examples)	• Instruction of the HNA tool 6 – 12 weeks after treatment at new end of treatment recovery clinic
Starting Date	October 2014
Completion Date	2 year project

Project Title	Tayside Phase 1
Cancer Type(s)	Colorectal, Urology, Head & Neck
Project Lead	Head of Nursing for Oncology and Haematology
Intervention/New Service	• Systematic use of HNA and end of treatment summaries (EoTS) in hospital and community settings by nurses and Allied Health Ps within the 3 cancer site specific teams • Nurse/AHP led programme of education on use of HNA and EoTS • Monthly Health and Wellbeing Events
Key Outcomes	• Improved knowledge & skills off assessment and care planning after treatment • All HNAs and EoTS shared with Primary Care • Improved signposting of patients (from H&W Events) • Increase number of patients on self-management programmes • Identification of gaps in community based services • Enhanced cross-boundary working • Reduction in routine consultant led follow up clinics • Increased number of nurse/AHP led clinics
Changes in Practice (examples)	• 3 cancer specific teams using HNA/EoTS • Hospital and community based nurses/AHPs in these teams provided with programme of education • Mapping/scoping of relevant services to support patients • Monthly health and wellbeing events to be set up
Starting Date	January 2015
Completion Date	2 year project

Project Title	Ayrshire and Arran Phase 1
Cancer Type(s)	Breast and colorectal
Project Lead	Macmillan Nurse Consultant (Debbie Provan – employed as project manager and is new lead)
Intervention/New Service	Introduction of eHNA and Care Plan at diagnosis and exit points (Clinical Nurse Specialists) and an end of treatment summary provided to the GP (Consultant or CNS) Using the eHNA and care plan at 6-8 weeks post-exit visit (and additional time points if required) by Health and Wellbeing Practitioners and results communicated to GP and CNS if required Set up a weight management/exercise programme
Key Outcomes	SHORT TERM • The service identifies needs of patients 6-8 weeks post-completion of treatment including late effects • GPs are aware of the treatment patients received, their needs and their plan of care • Practitioner awareness of the health and wellbeing model is increased • Patients have increased awareness of relevant support services and leading healthy lives (e.g. weight, alcohol, smoking, exercise) • Patients feel empowered and supported to take control of their lives • Reduced numbers attending review clinics leading to increased capacity for new breast cancer patients
Changes in Practice (examples)	• The introduction of eHNA and care plan at diagnosis by Clinical Nurse Specialists, an end of treatment summary to communicate plans to the GP and eHNA and Care Plan at 6-8 weeks post-exit visit (and additional time points if required) and by Health and Wellbeing Practitioners and results communicated to GP and a CNS if required • Mapping and scoping of relevant services to support the patients
Starting Date	January 2015
Completion Date	2 Year project

Project Title	Borders Phase 1
Cancer Type(s)	ALL
Project Lead	Macmillan Nurse Consultant AND Macmillan Lead GP cancer and Palliative Care Services
Intervention/New Service	• Undertake locality based patient education and support networking events • Introduce a locality based managed physical activity programme • Create links with community based resources • Introduce and use end of treatment care summaries and HNA's
Key Outcomes	SHORT TERM • Opportunities for joint partnership • Identify community resource • Identify self-management resources • Ensure the patient is actively involved in planning & managing own care • Creation of links with community based resources to promote healthy lifestyle choices
Changes in Practice (examples)	Introduce the HNA following initial treatment decisions and on completion of treatment, end of treatment summaries and education and support events
Starting Date	October 2014
Completion Date	1 year project

Project Title	Fife Lung Phase 1
Cancer Type(s)	Lung
Project Lead	Consultant in Palliative Medicine
Intervention/New Service	• Set up a "Best Supportive Care Clinic" • Introduce a rapid response service • Use a Holistic Needs assessment tool • Use End of treatment summaries • Use End of treatment reviews Development of an integrated risk stratified patient care pathway
Key Outcomes	• Reduce number of unplanned admissions to hospital • Reduce number of routine follow ups in secondary care • Improve the quality of life for people with advanced lung cancer and their families/carers • Patients play a more active role in their care and feel more supported in dealing with physical;, emotional and financial issues • To provide more of their care to be provided in the community and in a timely manner
Changes in Practice (examples)	• The introduction of a best supportive care clinic offering patients timely care within a week of referral. • Rapid access to health/social care if required through the development of a 24/7single point of access specialist palliative care service and an enhanced integrated communication process with hospital and the community • Increased collaboration and integration between services and practitioners
Starting Date	February 2015
Completion Date	2 year project

Project Title	Dumfries and Galloway Phase 1
Cancer Type(s)	Breast
Project Lead	Lead Cancer GP
Intervention/New Service	• Transfer follow up of breast cancer patients from hospital to primary care (Enhanced Service mechanism with GP sub / LMC) • Develop End of Treatment Summary (EOTS) • Health Needs Assessment (HNA) done at transfer by breast cancer nurse
Key Outcomes	• Transfer of responsibility for breast cancer follow-up to Primary Care • HNA enables better understanding of patients' "actual" needs • Patients return to a more "normal" lifestyle • Patients are more empowered • Patients access appropriate community resources • Better liaison with Social Services
Changes in Practice (examples)	• Develop protocol and Primary Care IT systems including new Read Code • Training for Primary Care teams • Follow-up in Primary Care at point determined by breast team • Work with established community services
Starting Date	January 2015
Completion Date	2 year project

APPENDIX THREE: Proposed Core Data Request

(To be completed for all patients/clients)

Unique Project ID Number	**Unique Patient ID**		
SEX	Male	Female	
AGE AT FIRST CONTACT		**Date of first appointment/attendance at TCAT project/service**	
POSTCODE	**SIMD 2012 Rank/Vignitile:** **Once entered you must DELETE postcode before sending to ENU**		
Cancer type (PLEASE WRITE IN)		**Date of diagnosis (PLEASE WRITE IN)**	
STAGE OF CANCER		**CURRENT LIVING SITUATION**	
Primary	1	Living alone	1
Secondary	2	Living with spouse/partner	2
Not known	99	Living with children/relatives	3
ETHNICITY		Living with friends	4
White, Scottish	1	Living in sheltered/nursing home	5
White, Irish	2	Not known	99
White, Other	3	**ECONOMIC ACTIVITY**	
Mixed	4	Employed	1
Asian, Indian	5	Self Employed	2
Asian, Pakistani	6	Unemployed	3
Asian, Chinese	7	Retired	4
Asian, Other	8	Student	5
African, Caribbean, Black	9	Looking after home /family	6
Other	10	Long term sick or disabled	7
Not Known	99	Not Known	99

ECOG PERFORMANCE STATUS	
Fully active, able to carry on all pre-disease performance without restriction	0
Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work	1
Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours	2
Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours	3
Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair	4
Dead	5
Not Known	99