Transforming Care After Treatment National Programme Evaluation

Interim Report: 1 June 2016

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TRANSFORMING CARE AFTER TREATMENT INTERIM REPORT

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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.

EXECUTIVE SUMMARY

Introduction

Transforming Care After Treatment (TCAT) is a five year programme funded by Macmillan Cancer Support Scotland. TCAT is a partnership between the Scottish Government, Macmillan Cancer Support, NHS Scotland, local authorities and third sector organisations that focuses on the care and support of people after treatment for cancer.

In order to evaluate the national programme, Edinburgh Napier University employed a mixed method study using two theoretical approaches - Realistic Evaluation and Appreciative Inquiry. This ensured the evaluation was solution focussed and could answer the question "what works, for whom and in what circumstances"?

This report builds on the early programme scoping work presented in the Baseline Report (March 2015)[1] by setting out the progress made and the impact of TCAT to date. In summary these are:

- Developing innovative and community based approaches to care after treatment
- Demonstrating partnership working and health and social care integration
- Increasing user involvement and the patient voice
- Improving health and social care data
- Understanding and improving resource use
- Positive prospects for sustainability

Half way through a five year programme it is not possible to answer fully all of the set evaluation questions (page 11). At the time of writing, only one local project has completed, six will complete in 2016 and the remainder (18) not until late 2017. This Interim Report therefore has four purposes.

1. To set out what is known about the impact of TCAT to date, by highlighting progress in key priority areas and illustrating the programme's potential to support solutions and contribute positively to the strategic and operational demands faced by health and social care services in Scotland.
2. To present interim data collected that describes 'assessment' practice and resulting actions such as: timing of the assessment, length of consultation, and the scale and pattern of formal referral and signposting activity.
3. To present final findings related to the programme's processes to date, by focussing upon the design and, implementation of TCAT and sharing key lessons learned to enhance operational and strategic level working.

4. To set out the recommended next steps designed to ensure a robust outcomes focused evidence base.

Interim findings and lessons learned

Taken separately and as a whole the 25 TCAT projects are testing new models of health and social care directly relevant to the 2020 Vision and new National Health and Wellbeing Outcomes [2].

Nineteen projects are testing after treatment assessment in different settings, locations and by different professions.

After care assessment in different settings:

- In hospital (mainly in out-patients (9 projects)
- a primary care setting (1 project)
- wider community settings (9 projects)

And by different professions:

- Clinical Nurse Specialist /Clinic Nurse (8 projects)
- Doctors, Allied Health Professionals (3 projects)
- Non-health care assessor (8 projects)

At this interim stage, 865 people have been assessed and data was available for 405 people from 6 projects who completed a Concerns Checklist at the end of their treatment. Of these, almost three-quarters (298) had one or more concerns at this time, collectively citing a total of 1,492 concerns.

Table EX1: Concerns identified after treatment

Category of Concern	As a % of all people assessed	No. of people with a concern of this type
Physical	62.7	254
Emotional	27.2	110
Practical	20.2	82
Lifestyle or Information	17.3	70
Family, Relationship	8.6	35
Spiritual or Religious	3.7	15
		(n=405)

The 10 most frequently identified concerns are shown in the table below.

Table EX2: Ten most frequently identified concerns after treatment

Concern identified	%	(n)
Tired/exhausted or fatigued	24.9	101
Hot flushes/sweating	19.0	77
Worry, fear or anxiety	17.8	72
Sleep problems/nightmares	16.3	66
Getting around/walking	14.3	58
Pain	14.1	57
Eating or appetite	12.8	52
Memory or concentration	12.6	51
Dry, itchy or sore skin	12.1	49
Tingling in hands/feet	11.1	45

Macmillan Cancer Support acknowledge that "large scale transformative programmes of work take longer to deliver and even longer to see the full results"[3]. While there are few 'quick wins' in cultural and transformational change, the interim findings have identified 'early impact' and demonstrated the contribution TCAT can make to key strategies, policies and local operational decisions across Scotland.

> There is a need to review and re-focus the planned evaluation activity to ensure a robust outcomes-focused evidence base that secures TCAT's role in making a significant contribution to current issues faced by providers and the national strategic priorities of health and social care in Scotland today.

Change on this scale is providing significant national and local data and intelligence and is giving rise to vital local and regional learning. In addition, a picture of the needs of patients living with a cancer diagnosis at end of treatment is being developed by the work of the TCAT programme.

> There is potential to link the emerging TCAT data with other Macmillan and national data sets in the future.

At the interim stage of a five year programme, TCAT's role and reach is significant. Over the next two years its contribution to the care provided to people affected by cancer specifically, and the enhancement of health and social care provision in general, will increase.

TCAT has resonance in Scotland and further developments should link themselves to this ‘brand’.

The evaluation has found that there is value for local projects in developing new models of care within a ‘national programme’ and that the reputation and expertise of the funder is required and appreciated by projects.

High profile programmes of ‘transformational change’ result in equally high expectations, and programme leads need to strategically and operationally manage these.

Whilst a range of design and structure issues and implementation related challenges have been identified, there was consensus that the structure had the anticipated potential to contribute to TCAT’s principles of: improving practice outcomes and experiences; enhancing service integration and coordination; and maximising sustainability and roll out. The phased approach and iterative build-up of the support structures for the programme has, however, given rise to a number of delivery delays and challenges.

The programme has engendered and maintained strong commitment from stakeholders. However, implementation in some areas has been slow and dominated by local operational issues, to the detriment of the overall strategic management of the transformational vision.

A key lesson is the need for early support/capacity at the development/design stages of projects to better develop operational plans at the expression of interest stage. In addition, limited evaluation capacity and resource at a local level will undermine the value of the growing evidence base.

At all levels of the TCAT structure there is a need for better understanding of roles and responsibilities. This would be aided by (a) the dissemination of a clear ‘vision’ for TCAT (b) stronger communication channels and (c) work to increase knowledge and understanding of the working practices and environments of all involved stakeholders.

TCAT is having a direct, positive impact on increasing partnership working in the field of cancer care. TCAT can be viewed as a catalyst for partnership working and the development of improved cancer service integration/coordination, which should be used as demonstration sites to inform other long term conditions. At a local level, there are new networks and connections which will strengthen the ongoing development and sustainability beyond the life of TCAT.

> For TCAT to successfully enhance service integration and coordination of care after treatment services and support, it will have to maximise the opportunities the programme has provided and work to ensure that developing partnerships are not short lived or merely TCAT specific.
>
> The way in which the Cancer Networks can add value to service integration and co-ordination should be given continued priority.

TCAT provides a valuable opportunity to explore and develop innovative approaches to engaging people with experience of cancer in the design and delivery of services. Given the emphasis on this within the national cancer plan, there is a parallel need to further promote and sustain TCAT's aspirational moves from individual patient representation and facilitate more innovative approaches to increasing the influence of patients, carers and the public. However, to date this important aspect of the TCAT programme has not been adequately determined, resourced or assessed.

> Moving forward TCAT, at all levels, should aim higher in relation to being an exemplar of patient influence in a transformative programme of change. This aspect of the programme requires review and targeted implementation and evaluation.

Crucial 'building blocks' for capitalising on the foundation work and maximising sustainability and roll out of TCAT activity are leadership, ownership, commitment and an ability to influence attitudes, behaviours and priorities**.** The structure of TCAT supports the principle and aim of sustainability to be achieved at national, regional and local levels. Local ownership of projects has built a positive platform for sustainability complemented by regional network involvement and responsibility.

> There is a need for dedicated effort to strengthen the 'building blocks' of sustainability identified in this report. In addition, the actual vision of sustainability and roll out (known as Phase 3 of the TCAT Programme) needs to be voiced with clarity as early as possible to enable the multi-layered leadership of the programme to maintain interest.
>
> For a programme to maximise sustainability, it is important for leaders to concentrate on not losing the momentum as TCAT moves into the end of its 'formal' programme stage.

Interim recommendations

1. There is particular added value in the national evaluation being more proactively involved in local evaluation work for an agreed number of projects.
2. In order to better understand new models and approaches to assessment and care planning and how they impact on costs and outcomes, future evaluation work should examine differences across the local projects as a means of 'fine testing'. This will help to answer questions around the impact of the setting and person delivering the assessment.
3. It is recommended that data from TCAT on 'identified concerns' at the end of treatment be further examined and used to inform new models of care.
4. That there is a new reporting and dissemination strategy (see page 54) to enhance implementation of evaluation findings nationally, regionally and locally.
5. The second phase of evaluation should focus on the way in which organisations work to better integrate and coordinate services in order to improve outcomes and experiences for patients/service users.
6. The development and funding of a robust programme of work, focussing upon the influence of people affected by cancer in service design and delivery.

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PURPOSE AND STRUCTURE OF THE INTERIM REPORT

Introduction

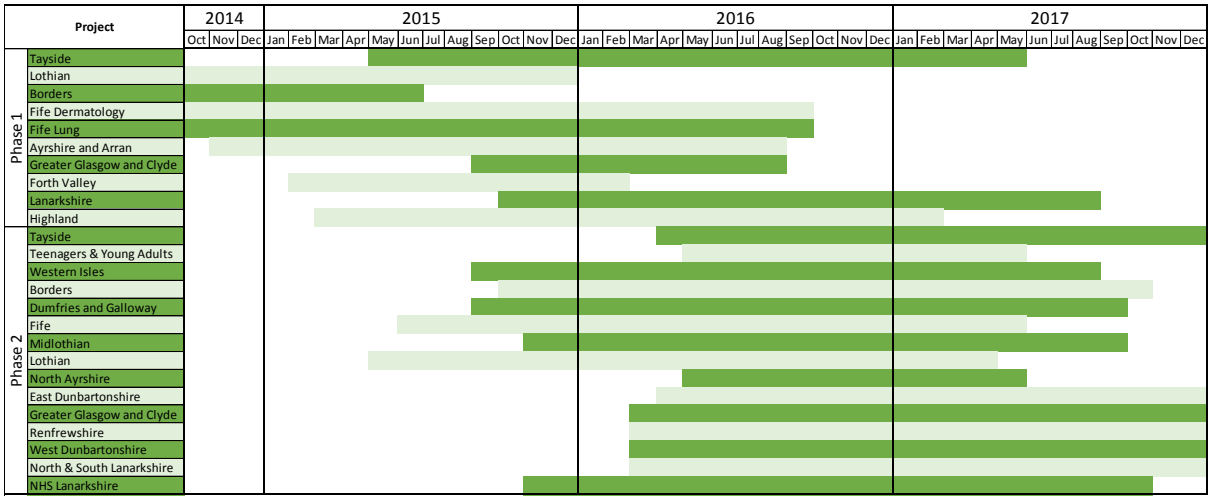
Transforming Care After Treatment (TCAT) is a five year programme funded by Macmillan Cancer Support Scotland. TCAT is a partnership between the Scottish Government, Macmillan Cancer Support, NHS Scotland, local authorities and third sector organisations that focuses on the after care and support of people after treatment for cancer. The overarching aims of TCAT are to:

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

Purpose of Interim Report

This report builds on the early programme scoping work presented in the Baseline Report (March 2015).[4] Half way through a five year programme it is not possible to answer fully all of the evaluation questions. At the time of writing, only one local project has completed and a number are still in early stages of implementation.

Project Timelines – Phase 1 and 2



In addition, as a programme develops it is necessary to review the utility of the original evaluation focus and scope. This Interim Report therefore has four purposes.

1. To set out what is known about the impact of TCAT to date, by highlighting progress in key priority areas and illustrating the programme's potential to support solutions and contribute positively to the strategic and operational demands faced by health and social care services in Scotland.
2. To present interim data collected that describes 'assessment' practice and resulting actions such as: timing of the assessment, length of consultation, and the scale and pattern of formal referral and signposting activity.
3. To present final findings related to the programme's processes to date, by focussing upon the design and, implementation of TCAT and sharing key lessons learned to enhance operational and strategic level working.
4. To set out the recommended next steps designed to ensure a robust outcomes focussed evidence base.

METHODOLOGY TO DATE

Introduction

Edinburgh Napier University were commissioned in June 2014 to undertake an independent evaluation of the programme by addressing set Evaluation Questions.

TCAT National 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/or a more appropriate use of resources than current practice?

Process

9. What have been the benefits and drawbacks 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?

In order to answer the questions, two theoretical approaches have been used in combination by the Edinburgh Napier University Evaluation Team. The evaluation is adopting a Realistic Evaluation framework with an Appreciative Inquiry approach.[5] [6]

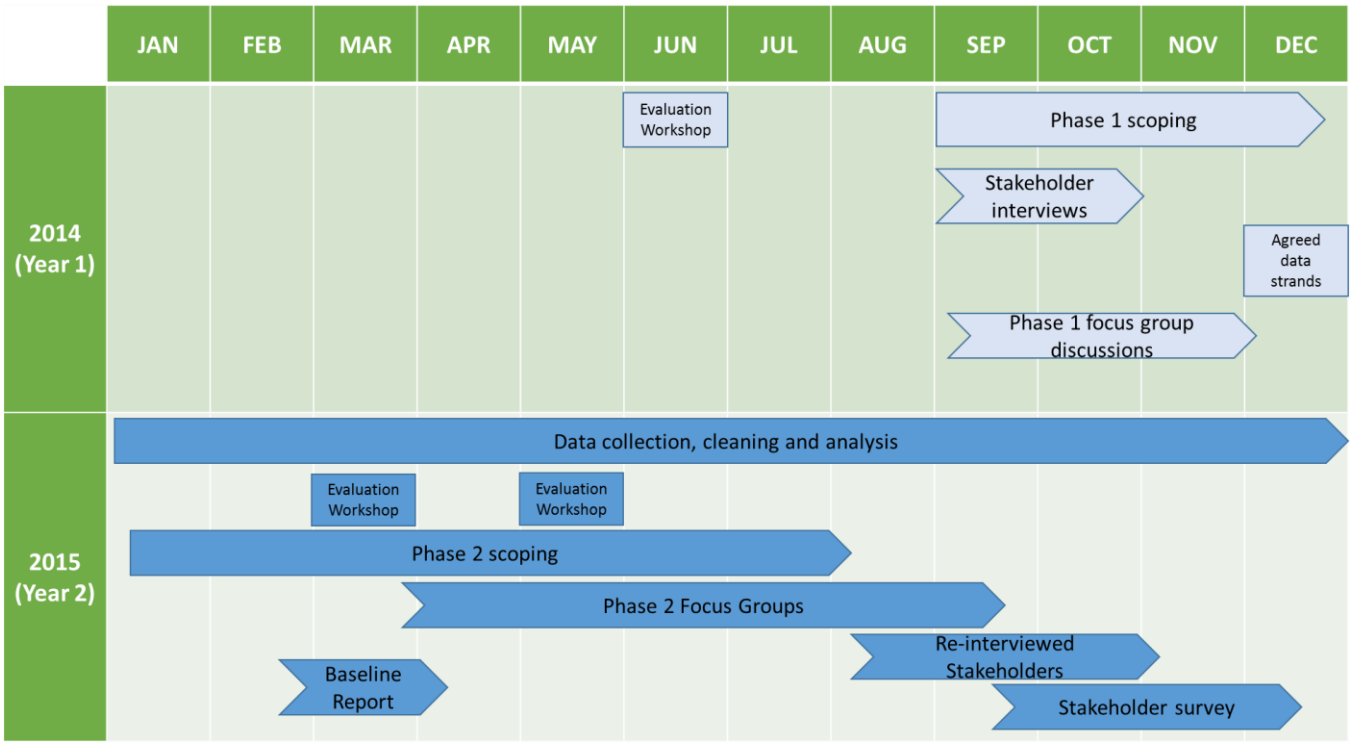
Realistic evaluation focuses upon identifying and making sense of the context, the mechanisms of action and outcomes of care after treatment. Paying attention to each of these connected concepts enables a depth of understanding of each project.

Appreciative inquiry focuses on identifying what works well and taking time to understand why this is so then adapting practices to capture more moments of success. Working with an appreciative approach in TCAT aims to support practitioners to look at their project through an appreciative lens, what is working and what possibilities exist? The evaluation team have embedded an appreciative approach into fieldwork tools such as interview and group discussion topic lists and online survey questions.

This combination of approaches is valuable as the national evaluation covers numerous local multi-component interventions within a complex regional and national programme. The TCAT programme in Scotland is not one model of ‘care after treatment’ set up in different locations, but 25 different interventions/projects that are linked by the programme’s overarching aims. They have one destination but many routes to success.

Methods

The key work strands of the mixed method evaluation are summarised in the diagram below. (Full details and copies of the fieldwork tools can be found in a separate report - TCAT Technical Appendix to Interim Report).



Groundwork and Scoping

Using an analysis framework of the key TCAT programme components, devised by the Edinburgh Napier University Evaluation Team, each of the 25 projects was defined and scoped. Particular attention was paid to the key aims of the programme overall and specific elements of the Recovery Package.

Focus group discussions

Fourteen focus group discussions have been held with projects at the end of their development stage/early implementation stage. The discussions gathered the views and experiences of local projects in relation to their: aims, set up challenges and solutions, the role of TCAT programme structures in their work. In addition early views on key programme aims such as service integration, attitudes to 'after care' for people affected by cancer and the potential for sustainability and /or roll out were sought.

Table 2: Focus Group discussions by Phase

	Number conducted
Phase 1	**8**
Phase 2	**6**

Within each group discussion the number of participants ranged from 2 to 11. A total of 64 participants took part.

A second focus group discussion will be held with these projects at the end of their projects and to date this has been carried out with the one completed project.

Interviews with core stakeholders

In 2014 in-depth interviews with representatives of the programme's governance structures (n = 11) were undertaken. During November 2015 these were repeated with nine and two representatives from the North of Scotland were interviewed for the first time. Throughout this report they are referred to as 'core stakeholders'.

Online survey of wider stakeholders

An online survey of 195 wider TCAT stakeholders was distributed online in November 2015. These wider stakeholders included members of national and regional TCAT structures and those involved in Phase 1 project implementation steering groups. The overall response rate was 55% - relating to 108 people. However a number only answered the first question before exiting the survey and have been removed from the overall analysis. The sample also included Phase 2 projects and they too have been removed from this reporting.

A significant number of wider stakeholders have more than one role – for example representatives from local projects are members of regional steering group in their area. The useable sample for this report is therefore 64 wider stakeholders who have 79 roles in TCAT. Throughout this report they are referred to as 'wider stakeholders.'

Table 3: % response rate by role in the structure

	Responses	
Roles	%	(n)
Programme Board	31.8	7
Regional TCAT Implementation Group	43.1	19
Phase ONE local Project	37.9	53
		79

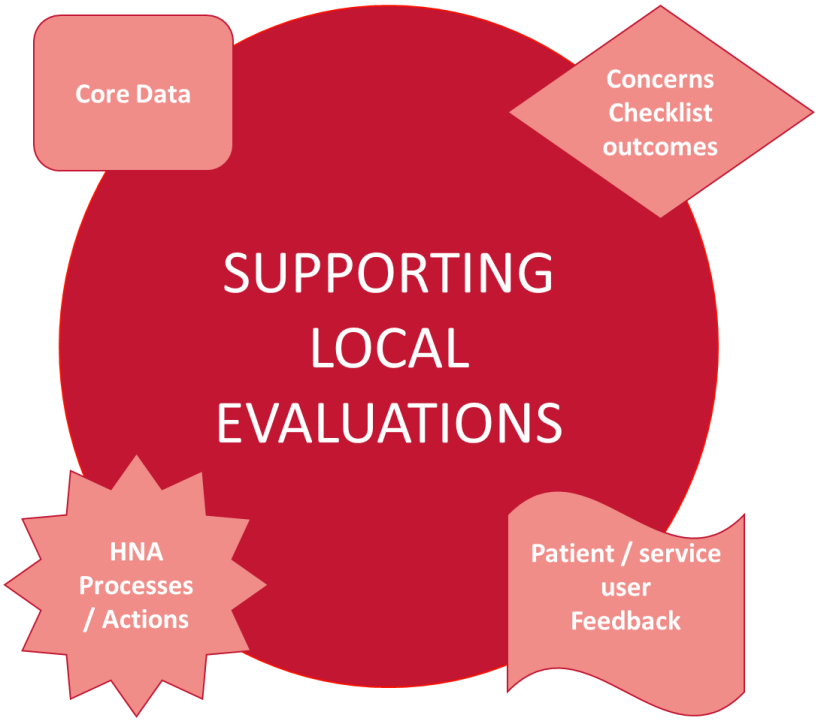
The respondents to this survey are representative of the number of 'wider stakeholders' within SCAN, WoSCAN and NOSCAN.

Table 4: Response rate by region

	Responses	
Region of Respondent	%	(n)
West of Scotland (WoSCAN)	39	25
South East Scotland (SCAN)	44	28
North of Scotland (NOSCAN)	17	11
		(n=64)

Data gathered for National Evaluation

Edinburgh Napier University devised four data sheets to gather data from local TCAT projects. In various combinations, these can be used by all projects, irrespective of setting, for example hospital or community. These are presented in the Technical Appendix and summarised in the diagram below.



Core Data: is collected for all the patients/clients/users of TCAT services/interventions across the whole programme in Scotland and provides basic demographic information. It includes for example, cancer type, age and living situation.

HNA Processes and Actions: is a data sheet used to record key aspects of the assessment undertaken, regardless of the HNA tool used, such as profession undertaking the assessment, location, length, referral and signposting activity.

Concerns Checklist: is a record of the identified concerns and overall concern level/score of individuals within the TCAT programme who locally completed a HNA using the Concerns Checklist tool only.

Patient Feedback: is gathered directly from patients/service users of participating local projects using the questionnaire devised by Edinburgh Napier. In addition a questionnaire for use before the TCAT intervention to provide baseline data was developed to assist with gathering baseline data.

Data is gathered by projects and transferred to Edinburgh Napier University. The data used at this Interim Stage is shown in the table below. It shows the number of patients/service users engaged in the programme (core data) and the scale of end of treatment assessments carried out (Assessment Process/Actions) between October 2014 and December 2015. Data on the concerns identified using the Concerns Checklist was submitted in relation to 429 individuals over the same time period.

Table 1: Data Used in March 2016 report * - end of treatment assessment only

	Core Data	Assessment Process / Actions	Concerns Checklist Data
NHS Borders	61	45	32
NHS Lothian	83	56	56
NHS Lothian (prostate only)	105	0	0
NHS Fife (Lung)	192	174	0
NHS Fife (Dermatology)	77	77	77
NHS Tayside	107	107	107
NHS Ayrshire & Arran	86	86	86
NHS Forth Valley	132	47	47
NHS GGC	24	24	24
TOTAL	867	616	429

*The NHS Lothian Phase 1 project provided data for the 2 service developments within their project – one of which focussed solely on people with prostate cancer

Ethical approval was obtained from Edinburgh Napier University internal committee to undertake the evaluation work detailed here. National approval for the collection of NHS generated data was granted in June 2015 by the NHS Scotland Caldicott Guardian Scrutiny Panel.

Analysis

All qualitative data were subjected to thematic analysis[7]. Transcripts were firstly listened to and read to check the accuracy of the text and then coded using the software, QSR NVIVO. This was then verified independently by three other members of the team for consistency and interpretation.

All quantitative data was reviewed for accuracy and omissions. The Research Fellow worked with the statistician and local projects to ensure the submission and analysis of only robust data. The data was analysed using Excel and SPSS.

Health Economic Evaluation

A work plan for this was agreed in February 2016 and will report this year and next on nine selected projects.

BACKGROUND AND CONTEXT OF TCAT

Introduction

Across the United Kingdom the numbers who are living with a cancer will increase from 2 million to 4 million by 2030. For Scotland, this is an increase from 190,000 in 2010 to around 340,000 by 2030 if current trends continue[8].

Data on healthcare utilisation indicates that there is a significant level of health care usage in the period 1-5 years after diagnosis[9]. In addition, of the 65 and over age group living with cancer, many have co-existing diseases (co-morbidity)[10].

In common with other long term conditions, the provision of effective and sustainable cancer survivorship services, requires reform of the planning, delivery and performance of health and social care services to ensure appropriate use of resources, improved outcomes for patients and carers, support for self-management and an overall and ongoing shift in focus from treating the disease to overall health and wellbeing.

Background and context

The background to TCAT is linked to the Christie Commission on the 'Future delivery of Public Services (2011)[11]. The Commission believed that 'rising demand and costs pressures compounds the impact of Scotland's tightening budgets' and recommendations included:

- a presumption in favour of preventative action and tackling inequalities
- concentrating the efforts of all services on delivering integrated services that delivered results

These recommendations and others were included in the Scottish Government's strategic vision for health care services 2020 Vision[12] envisioning a health care system fully integrated with social care and focused on:

- prevention
- anticipatory care
- supported self-management
- an expansion of GPs and their roles
- managed flows through hospital services

A 'route map'[13] for the vision was published in 2013 developing an improvement framework and strategic commissioning as well as workforce development.

In 2014 the Scottish Government signalled a move from strategic encouragement towards legislative duty and guidance with the 'Public Bodies (Joint Working) (Scotland) Act 2014[14]. The Act required NHS Boards and respective Local Authorities to establish integration schemes, joint budgets, structures and governance. The new Integration Authorities had to be operational by 1 April 2016 and the Government issued guidance on assessing performance through the 'National Health and Wellbeing Outcomes in February 2015[15]. A key legislative requirement was that Integration Authorities/Integrated Joint Boards had to produce a strategic plan for their areas based on local needs.

The relevance of the TCAT programme to the integration and other reform agendas can also be seen in the 2015 report of the Auditor General. Her report, 'Changing models of health and social care (2016)16 concluded that:

- the shift to new models of care is not happening fast enough to meet the growing need
- NHS Boards and Councils can do more to facilitate change including focusing funding on community based models and workforce planning to support the new models and have a better understanding of the needs of their local populations
- a better understanding of the needs of local populations is required
- new models of care had to be evaluated "properly" and learning from this be coordinated and accessible

TCAT was designed to address many of these challenges by providing strategic direction and drive for new, integrated follow up /after care models relevant to the wider reform of public services including:

- developing new models of care to address unmet needs and wider service challenges
- maximising the sustainability and roll out of evidenced based practice
- enhancing service integration and coordination and health and social care partnership working in relation to services for people affected by cancer
- providing cost effective solutions and a more appropriate use of resources than current practice

Twenty five projects are testing different 'combinations' of the recovery package elements, a key delivery mechanism for TCAT. The interventions are: Holistic Needs Assessment, Treatment Summaries, Cancer Care Reviews, and Health and Wellbeing Events. These elements combine to support self-management through, for example, physical activity as part of a healthy lifestyle, managing consequences of treatment, and information, financial and work support.[17]

Operationally and strategically, TCAT mirrors the aspiration of the Scottish Government's 2016 Cancer Strategy "Beating Cancer: Ambition and Action".

> *"for health, social care and third sector services to deliver sustainable and innovative approaches to cancer care which meet the changing requirements of people with cancer to support them to live healthy lives at home"* [18]

INNOVATIVE APPROACHES TO CARE AFTER TREATMENT

"we want people to access services because of design not luck" (Project)

The scale of innovation

TCAT has been 'operationalised' via the commissioning and funding of local projects, tasked with the development, testing and evaluation of new models of service delivery and practice. At present there are 25 operational 'TCAT Projects' in Scotland (1 national and 24 local). In December 2013 ten Phase 1 projects were granted funding and a year later 15 Phase 2 projects came on stream.

The bottom up programme design resulted in diversity in approach to changing models of follow up across Scotland and has seen local responses to address identified needs and service gaps.

Taken separately and as a whole the 25 TCAT projects are testing new models of health and social care directly relevant to the 2020 Vision and new National Health and Wellbeing Outcomes [19]. For example enabling and supporting self-management was found within the specific aims or planned outcomes of all TCAT projects in -patient related aims referring to reablement, confidence and empowerment.

Change on this scale is providing significant national and local data and intelligence and giving rise to vital local and regional learning as to 'what works' for whom and in what circumstances.

The summaries of seven of the TCAT projects below illustrate the range of innovative approaches within the TCAT Programme.

North & South Lanarkshire Councils

Supporting people after treatment with individual budgets

This project will support people to think about what would make a difference to their life after treatment. Crucially this will be facilitated by a small individual budget to allow them to pursue something they have identified will be beneficial to their recovery and wellbeing.

Both the person affected by cancer and members of health and social work staff will attend co-production sessions to support the planning and spending of the budget and those involved in the intervention will be supported by an Local Authority staff member.

NHS Greater Glasgow & Clyde

Cognitive Rehabilitation and Support Following Cancer Treatment

This project aims to raise awareness, knowledge, skills/confidence in health, social care staff and 3rd sector employees in the identification and support of patients who are experiencing Cancer Related Cognitive Impairment (CRCI). This will be done through:

- provision of teaching/training of staff in health and social care sectors
- compiling information resources for use in all settings (and relevant self-help materials)
- delivering a group based intervention to those who present with more complex CRCI

East Dunbartonshire

TCAT Community Outreach Project

To assist in the development of an infrastructure to identify, support and empower people impacted by cancer, which will help reduce social isolation, improve pathways following discharge from hospital, improving the co-ordination of the available support and establish better networks. The project will employ a Development Worker who will:

1) Facilitate a review and redesign where appropriate existing cancer health improvement pathway between Acute, Primary care and other stakeholders
2) Promote self-management and peer support through the development of and support for groups led by people with cancer
3) Review use of holistic assessment tools used within the catchment area with a view to developing a common outcome focused support plan used across health, social care and third sector
4) Coordinate the delivery of a population level cancer awareness raising programme
5) Coordinate further enhancement of the East Dunbartonshire Community Asset Mapping Project to more effectively support people recovering from cancer (an online resource of community organisations/sources of advice/support)

NHS Lanarkshire

Lung Cancer Local Development Project

To implement e-PROM (remote monitoring system) follow up processes to improve the quality of support provided to patients with lung cancer.

NHS Highland

Mycancerportal.co.uk

Aim to build and pilot a dedicated web portal visible to cancer patients and clinicians. Initially development will focus on colorectal cancer patients within NOSCAN area.

3 Ayrshire Councils

TCAT Employability Project

This Ayrshire wide project aims to support people diagnosed with breast cancer and colorectal cancer since January 2015 and anyone diagnosed with a head and neck or gynaecological cancer since January 2016 with integrated and tailored employability support to develop the skills and confidence to return to work or to pursue business opportunities.

Other activities will develop a greater awareness amongst local businesses to facilitate more supportive relationships with people affected by cancer, for mutual benefit.

NHS Tayside

Late Effects of Pelvic Radiotherapy

This project aims to help and support patients who have symptoms related to previous pelvic radiotherapy by offering them a Holistic Needs Assessment at point of referral and signposting them to relevant services, that might be nearer their homes or to community based facilities.

During the project a bespoke 7 week course on cancer survivorship for patients who have had previous pelvic radiotherapy will be developed in collaboration with colleagues at Maggie's centre. The main focus of the project is about supported self-management and referral to existing pathways of care or community based support, working in collaboration with local authority, third sector and secondary care partners.

Holistic Needs Assessment

Nineteen projects are testing the use of an assessment and care planning tool. Of these, 14 are testing the use of the Patient Concerns Checklist (See Technical Appendix). In addition, TCAT will provide local findings on the use of a number of other assessment tools, including:

- Sheffield Profile for Assessment and Referral for Care
- Canadian Occupational Performance Measure
- developments of current assessment protocols (such as prostate specific assessments, multi-disciplinary protocols for lung and Self Directed Support assessments)

- locally developed ‘questionnaire’ to assess the needs of patients with breast cancer

TCAT is testing after treatment assessment in different settings, locations and by different professions. Understanding the impact of these variables on patient experiences, outcomes and resource use will be of immense value to health and social care providers.

Range of settings and professions in TCAT assessment and care planning projects

After care assessment in different settings:

- In hospital (mainly in out-patients (9 projects)
- a primary care setting (1 project)
- wider community settings (9 projects)

And by different professions:

- Clinical Nurse Specialist /Clinic Nurse (8 projects)
- Doctors, Allied Health Professionals (3 projects)
- Non-health care assessor (8 projects)

One project (NHS Fife Lung) assessed over half (55%) of people in their own homes and nearly a further 20% as in-patients. As these patients were part of a ‘best supportive care’ service for advanced lung cancer, this is not unexpected. Assessment by telephone was a model tested by NHS Borders Phase 1 where 1 in 5 assessments (23%) were done this way.

The summaries below provide details of TCAT projects testing assessments in hospital settings.

NHS Ayrshire and Arran

Health and Wellbeing Model of Breast and Colorectal Cancer Follow Up

Breast Cancer: Project will develop the use of electronic Holistic Needs Assessment (eHNA) and care plan at diagnosis and end of treatment. A Health and Wellbeing Practitioner is employed to carry out an eHNA 6 – 8 weeks post active treatment in a community setting. Signposting and referral will be supported through the development of a support directory. Exercise and weight management classes will be developed and other health and wellbeing interventions will be actively promoted.

Colorectal Cancer: Project will develop the use of eHNA and care plan for surgical (~6 weeks post op) and adjuvant chemotherapy patients (~6 weeks post chemo). A Health and Wellbeing Practitioner is employed to carry out an eHNA and care plan 6 – 8 weeks later in a community setting. Signposting and referral will be supported through the development of a support directory. Exercise and weight management classes will be developed and other health and wellbeing interventions will be actively promoted. An End of Treatment Summary will be completed and sent to the patient and their GP following surgery and/or chemotherapy.

NHS Lothian

Developing a recovery based approach to cancer in Lothian

The overall aim of this proposal is to evaluate the benefits of a recovery-based approach to care in patients treated for prostate, breast, gynaecological, anal/rectal and lung cancer. Around 6 – 12 weeks post treatment and again at 6 months, patients will attend clinic and an HNA will be carried out along with a care planning. A summary of the consultation will be sent to the GP.

NHS Borders

Locality Based Health and Wellbeing Support Programme for people with cancer

Piloted with 61 patients, 1 year funding completed in July 2015.

The overall aim of the project was to enhance patients' health and well-being by providing integrated support which is relevant to individual needs and promoted independence and healthy lifestyles.

To do this, the project offered the following package of measures via a locality based approach:

- Completion of HNA after diagnosis (if relevant) and at end of treatment
- Creation of individual care plans based on HNA
- Locality based Health and Well-being Events at the end of treatment
- Creation of links with community based resources to promote healthy lifestyle choices
- A directory of services was created – health, social, community groups
- End of Treatment Summary for Patient and GP

NHS Forth Valley

Prostate Cancer Project TCAT

To restructure follow up and HNA of men with prostate cancer to a community based, nurse led model. Staff employed by TCAT project will link to One to One project.

NHS Greater Glasgow & Clyde

NE Sector TCAT Project

The NE Sector Breast Service TCAT project tests a new model of person centred care. This imaging-led model of care, focuses on, supported self-management and annual imaging. This model aims to support patients transitioning from acute to community, reducing unnecessary hospital contact and enhancing quality of life. As well as improving communication across all sectors and ensuring patients have an appropriate individually tailored follow up plan.

NHS Tayside

TCAT in Tayside

Aim to establish and test a health and social care integration approach – focussed on rehabilitation. This will include the mapping of existing pathways and services in the local communities. The use of HNA and end of care treatment summaries for head and neck, urological and colorectal cancer patients is planned. Initial focus will be on colorectal cancer. The project also will involve staff/ patient education and regular health and wellbeing events.

NHS Fife (Dermatology)

Melanoma – TCAT

Developing the role of the skin cancer link nurses. The aim is for 4 monthly follow up appointments to alternate between them and the Dermatology Consultant. HNA will be carried out at Link Nurse Appointments. Plan to set up self-management groups. Patients will be sent a copy of all their clinic/hospital letters. End of Treatment summaries will be sent to GPs

Interim data on whether the patient completed the checklist prior to the assessment consultation is available for five projects, and on the length of assessment for seven projects and shows variation in these areas of assessment practice.

Table 5: Whether patient completed checklist prior to consultation – Interim data from 5 projects

	NHS Forth Valley	NHS Fife Dermatology	NHS GGC	NHS Tayside	NHS Borders
	% ONLY				
YES	63.8	0	91.7	89.7	24.4
NO	36.2	100	8.3	10.3	75.6
(n)	(47)	(77)	(24)	(107)	(32)

Table 6: Length of assessment appointment/consultation – Interim data from 7 projects

	NHS Forth Valley	NHS Fife Dermatology	NHS Fife Lung	NHS GGC	NHS Lothian	NHS Tayside	NHS Borders
	% ONLY						
Up to 20 mins	76.6	70.1	-	100	3.7	51.4	17.2
20 to 30 mins	10.6	19.5	-	-	-	30.8	58.6
30 to 45 mins	12.8	5.2	11.5	-	46.3	15.0	13.8
45 mins to 1 hour	-	2.6	86.2	-	38.9	2.8	-
Over an hour	-	2.6	-	-	11.1	-	10.3
(n)	(47)	(77)	(174)	(24)	(56)	(107)	(45)

A person's diagnosis, treatment and end of treatment assessment is a very individual and unique journey/pathway. The time point within a patient's journey that an assessment is offered is of key importance, and TCAT is contributing intelligence as to when and how often an assessment is most effective. For example:

- Some projects are testing the use of after treatment assessments at two time points. For example, NHS Lothian Phase 1 and NHS Ayrshire and Arran Phase 1 are testing assessments after treatment and again around 6 – 8 weeks later.

A number of Phase 2 projects are actively considering doing so but have not made a firm reportable decision.

- 11 projects have introduced an 'additional/new' end of treatment assessment review point.
- Interim data shows that TCAT projects are testing the use of assessment tools at different stages on the 'after treatment' pathway within the period of increased usage of health care resources [20] (See Table 7).

Table 7: Time from diagnosis to assessment – Interim data from 8 projects

	%	(n)
Up to 1 year	65.1	385
1 year to 3 years	19.6	116
3 years or more	15.2	90
		(591)

Variation was also found in referral practices, with interim data showing the predominant 'referral' route from hospital based TCAT projects is to 'other' NHS services. For example data from 8 projects shows:

- 13% to 73% of those assessed are referred to own GP
- 9% and 46% of those assessed are referred to NHS non cancer services; and
- 4% to 50% of those assessed after treatment are referred back to cancer specific NHS services.

Such early data can only raise more questions than it can answer, as it cannot illuminate, for example, the finer detail of the consultation, the impact of the consultation and the longer term outcomes and effect on self-management.

To better understand new models and approaches to assessment and care planning and how they impact on costs and outcomes. It is recommended that the next steps for the evaluation should examine differences across the local projects as a means of 'fine testing'. This will help to answer questions around the impact of the setting and person delivering the assessment.

Such work would answer the critical questions the findings to date raise but cannot answer. These include:

- What is the impact of the actual design of the intervention/service delivery model?

- In what ways is self-management actually being promoted by the Recovery Package? (for examine triggers to self-activation and the added value of reablement context/focus for some assessments)
- How does the means of delivery, location and timing of assessment impact on outcomes and experiences?
- What is the role of the professional in the assessment?
- What prompts or triggers referrals and signposting?
- Who is 'being assessed' and what characteristics and concerns do they have that could inform the design and implementation of other new models of care?
- What were the benefits of undertaking the HNA process for the person and in what ways did it impact on their aftercare experience and outcomes – short and longer term?
- What can we learn from the people who report they have 'no concerns'?

End of Treatment Summaries

Across the TCAT Programme, nine local projects and the national project included a commitment to actually develop and/or introduce an end of treatment summary in their plans.

Looking at wider initiatives in this area of practice development, it is evident that TCAT has been a catalyst for developments in this important area. For example, additional money from Macmillan Cancer Support was provided to NHS Forth Valley to develop an IT based system for treatment summaries. This work continues and £30K was provided to each Cancer Network (WoSCAN, NoSCAN and SCAN) in 2015 from the Macmillan Cancer Support to support the implementation of Treatment Summaries.

Cancer Care Reviews

One local project is testing the feasibility of Practice Nurses carrying out Cancer Care Reviews using the Patient Concerns Checklist. This study involves 9 practices across south Lanarkshire who run a weekly 4 hour clinic. The Edinburgh Napier University evaluation team are working closely with NHS Lanarkshire to evaluate workload, patient acceptability and outcomes and changes in resource use, such as General Practitioner appointments.

This is an innovative way of addressing pressures on General Practitioner time and investigating the role of the wider primary care team. This vital primary care data, combined with community health and social care integration intelligence, could provide an infrastructure on which to support further initiatives in line with the new General Practitioner contracts.

NHS Lanarkshire

The aim of this project is to look at the feasibility and acceptability of Practice Nurses carrying out Holistic Cancer Reviews in General practices using the Concerns Checklist. Two Practice Nurses have agreed to test it and overall 10 Practice Nurses will undertake training to be able to undertake Cancer Care reviews in their own practices. Each Practice Nurse will run a weekly 4 hour clinic.

Baseline will look at the number of Cancer Care Reviews currently carried out in Lanarkshire and the views of people affected by cancer gathered via focus groups. Plan is also to survey GPs and gather data re the number of post diagnosis GP appointments etc.

Health and Wellbeing Events

Six local TCAT projects are implementing some form of programme, series or one off health and wellbeing event. They are in Tayside (2), Western Isles, Scottish Borders, Fife and Ayrshire and Arran. These events are diverse in scale, scope and timing of provision. Overall they have an emphasis on physical activity, managing the consequences of treatment, financial and work support and general 'information'.

Physical activity, nutrition and UV exposure, are key actions areas within the Scottish Cancer Strategy of 2016. Local TCAT projects are excellent examples of how these national 'actions' are being implemented on the ground and over the next two years their evaluations will contribute to the developing evidence in this area.

Improving awareness and use of community based services

TCAT is contributing to improving local awareness and use of already established community based resources.

Within TCAT, awareness of available local services and support is targeted not only at people affected by cancer but also at health and social care professionals to inform more clear signposting practices. In time this work will inform better signposting to relevant services and support, as at this interim stage, signposting destinations after treatment are dominated by two cancer specific charities (Macmillan Cancer Support and Maggie's). This highlights the need for service mapping and awareness raising of the services available.

Ten local projects are working to 'map' the relevant services in their area to inform and improve referral and signposting practice. This important work has already changed practice in some areas. For example, the NHS Borders Phase 1 project developed a directory of services and support, which is now used by Clinical Nurse Specialists (CNS), the local Cancer Information and Support Service and NHS24. The 'Info for Me' service has engaged with NHS Borders to explore ways to include service information from this local TCAT Directory in their National Database. NHS Ayrshire

and Arran (Phase 1) have developed a Supportive Care Directory which is available to NHS staff via the intranet.

Developing new community based models of follow up

The development of viable and effective community based models of care after treatment is critical to the overall vision for health and social care provision in Scotland[21]. Within TCAT eight local projects are testing community based assessment/support services and pathways for people at the end of their cancer treatment. This scale and the variety of approaches being tested is providing much needed test sites for the robust evaluation of new ways of providing health and social care in community settings.

Fife Council

Integrated Community Cancer Care Project

Fife Council's phase 2 TCAT project aims to develop an integrated cancer care pathway with individuals being supported to access community services within a personalised outcomes focused approach to cancer care in the community. TCAT Local Area Co-ordinators will work with people affected by cancer to support them to overcome concerns and establish a good quality of life after cancer treatment. The project also works with individuals who have been affected by cancer and have connected with the Social Work Service and other NHS services.

The project links directly to the NHS Fife TCAT phase 1 projects (see pages x and x) to establish an integrated patient pathway from hospital care into the community.

NHS Lothian – Primary Care

Westerhaven Aftercare Project

This project is based at the Macmillan Wester Haven Cancer Support Service. Led by a GP it aims to ensure consistency/equity in assessment and subsequent access to support and information on completion of treatment.

The aim is to develop a 'protocol' for GPs at Wester Hailes Health Centre which incorporates making a direct and active link to Westerhaven (who will carry out and HNA.). Involvement by the GPs will be triggered by EOTS from hospital.

West Dunbartonshire Council

Macmillan TCAT Development Service

The emphasis of this project is to review and enhance the coordination and supply of after-care support services. An audit of around 50 patients and carers will be carried out to establish their experience following cessation of treatment and determine how to improve service provision. The Concerns Checklist HNA will also be piloted with 20 – 30 people who access services from Health and Social Care Partnership and Community Services and Carers of West Dunbartonshire. The project will be working closely withother partners and with GPs to ensure robust and effective pathways.

Scottish Borders Council & NHS Borders

The focus of this project is on social enablement and increased physical activity. The project takes a reablement approach to TCAT, triggered in Primary Care, to ensure that the functional skills and confidence levels of those post treatment are retained to enable participation in daily activities.

GPs (after a Cancer Care Review) will generate a letter inviting contact with an Occupational Therapist who will carry out assessment and make referrals. It is anticipated that this will enable an earlier transition into Social Work by offering assessment via Social Work Occupational Therapists. The project will use the assessment tool the Canadian Occupational Performance Measure. The project will refer directly to the British Red Cross Reablement Buddy Service

Dumfries & Galloway Council

Making Connections

Very much embedded in the local community, this project is managed by Building Healthy Communities, a partnership and community development programme, who offers a Self-Management Programme currently for people with Long Term conditions. Local authority partners (social work) are key to this work.

It aims to better support people including families and carers through individual support and involvement in activities and new opportunities that promotes improved quality of life and wellbeing. This will be supported by transforming how local services work together and improving/strengthening referral, signposting and awareness levels.

The project will employ 2 TCAT Workers to cover east and west of region who will accept referrals from various sources. These posts will have the Macmillan's Move More remit also. Assessment tools are under consideration however the project includes a small pilot of the Concerns Checklist.

Midlothian Council

Living Well After Treatment

The project team is aiming to improve the ongoing support of people living with cancer, enabling access to services through assessment, better signposting and information supporting people to manage their lives more effectively.

In keeping with the work being undertaken for people with Long Term Conditions (House of Care Framework) this project plans to develop a service based on a Local Area Coordination model. The service will respond, not only to the needs identified by the TCAT Phase 1 project at WGH, but for other people living with the consequences of cancer and treatment. Referrals will be taken from GP's, community nurses, hospitals as well as self-referrals. The TCAT Community Services Coordinator will act as first point of contact developing a triage system in order to make sure referrals receive appropriate support at the level required. The project will also work with and develop local services to provide and promote general advice, exercise, lifestyle management, dietary advice and a directory of 'after care' support and information.

NHS Western Isles

Looking Forward

The first stage of this project focusses upon recruiting a Project Officer who will scope the needs of patients across the various islands, collate a directory of resources, develop content of the planned programme and then by Year 2 develop and offer a programme of activities and events to meet these needs.

Overall the aim is to establish a programme of support, which will facilitate patients to progress onto a self-management pathway across the islands. Very much based on previous pilot programme "Looking Forward", the intention is that this will promote independence and activity of individuals and their families and for them to feel more confident in managing their condition and having the knowledge of where to access advice and support to help meet their individual needs.

Renfrewshire Council

TCAT Pilot

The Renfrewshire pilot is developing a recognised pathway at end of treatment for patients with breast and lung cancer, to support people with their individual needs as they return to their new normal.

The aim is for all patients at end of treatment for breast or lung cancer initially, to be referred to the community based TCAT service. Their needs will then be holistically assessed, using a recognised person centred tool (Patient Concerns Checklist) and a support plan, with a self-management focus, will be written.

In addition to being a catalyst for important understanding and learning, these TCAT projects and others demonstrate that TCAT is testing the working and viability of a set of models of integrated and coordinated services across the NHS local authorities and third sector.

DEMONSTRATING PARTNERSHIP WORKING AND HEALTH & SOCIAL CARE INTEGRATION

The Baseline Report identified early evidence of partnerships being formed around the local implementation of TCAT, at regional level via Network based TCAT work and by the establishment of a multi-sector TCAT Programme Board. Twelve months on, the number of local partnership groups and memberships of other TCAT structures have consolidated, and in some cases, expanded. While this is, in part, because Phase 2 projects are largely based out with secondary care settings, TCAT can be viewed as a catalyst for partnership working and the development of cancer service integration/coordination. As such, TCAT is having a direct, positive impact on increasing partnership working in the field of cancer care.

Various stakeholders share the view that TCAT is a good way of demonstrating partnership working at a local, regional and national level.

> *"working with our colleagues in social care … has been extremely positive. I can see that the collaboration will extend beyond the TCAT project and could be a great example of 'integration in action"* (Wider stakeholder)

At the operational level, there is evidence that local projects, primarily Phase 2, see partnership working across the sectors as the key to implementing their local project successfully. They prioritised engagement and involvement across a range of sectors in their early implementation and development processes.

A Phase 2 project in the Scottish Borders is the only project to have been jointly designed and led by an NHS Board and Local Authority. In addition, the new service is based within and operationally managed by a third sector agency – British Red Cross. This project and others highlights TCAT's ability to demonstrate and test models that will enhance integrated working.

One local project, in East Dunbartonshire, has been funded specifically to develop a strategic, integrated approach to their local cancer services and plans, which will include working in partnership to review current pathways, service provision and patient experiences and outcomes.

In two geographic areas, local TCAT projects have 'combined' and operate together under one steering group to enhance both service and strategic links. (NHS Lanarkshire and NHS Fife). For them, the impetus provided by TCAT was taken as an opportunity to enhance partnership working and service integration and coordination.

Improving service integration and coordination between different service providers is a key aim and principal of the overall programme, and, as such, TCAT embodies current policy and service re-alignment in Scotland.

The three cancer networks were tasked as part of their role in TCAT to support wider integration between health and social care. The national evaluation asked wider stakeholders for their views on how this regional role was adding value to improving integration between health and social care. 20% viewed the networks role as adding value to a great extent in this area, with 45% responding 'somewhat'. This is low in comparison to the rating given by wider stakeholders to the other programme roles of the regions (such as increasing clinical engagement and the patient voice).

In the context of the health and social care integration agenda there is much to be learned from closer evaluation of 'partnership working and service integration' from these TCAT demonstration sites. Moreover there is a major gap in understanding how people affected by cancer experience and benefit from integration. In addition the way in which the Cancer Networks add value to service integration and co-ordination should be given continued priority.

It is recommended that robust evaluation and research is commissioned over the next 2 years and targeted at the way in which organisations work to better integrate and coordinate services on the ground in order to improve outcomes and experiences for patients/service users.

INCREASING USER INVOLVEMENT AND THE PATIENT VOICE

Introduction

An overarching principle of TCAT is to increase service user involvement in service design and delivery and it was built into the aims and operational criteria and practices of all levels of the programme's structure.

Nationally, the programme has a Cancer Experience Panel (CEP) whose members all have lived experience of cancer. The CEP is supported by a TCAT Service User Involvement Manager, based at THE ALLIANCE. Locally, the criteria for programme funding of projects included evidence of "active and meaningful patient and public involvement within any proposed development project".[1]

TCAT Cancer Experience Panel

The CEP was established in 2014. This was after all of the phase 1 projects were agreed. The overall aim of the CEP is to:

> *"innovate and strengthen the approaches used to involve patients, carers and the public in the development of the cancer TCAT programme and hold the Programme Board to account for delivering improvements in patient experience"* [2]

One of its first roles was to contribute to the assessment process for bids for Phase 2 of TCAT. The CEP score was given a 50% weighting in the overall process and for many stakeholders, this was seen to signal loudly the importance of user influence within the programme. Other stakeholders did warn against this tangible role being seen as an end in itself, as opposed to one process in many.

Over the last 2 years the CEP has been represented by individuals at programme board and regional level and continues to work to strengthen patient and carer representation within local projects. However, their input has been affected by limited numbers of members, the availability of some members due to ill health and the delayed implementation of a number of local projects.

[1] Invitation to Tender, Macmillan Cancer Support, 2013
[2] TCAT Cancer Experience Panel Terms of Reference

User involvement at a local level to date

At the expression of interest stage, all TCAT projects were asked to document how users/people affected by cancer had been involved in the development of project proposals and to outline their plans for longer term user involvement.

A number of projects referred to feedback on current services by users/patients as part of their rationale and background to their proposed TCAT project. For some, this was anecdotal feedback (8), for others, relevant but non-specific survey/feedback activity to inform their proposed service delivery priorities (10). Four projects had gathered user/patient feedback on their specific TCAT project proposals.

All projects have undertaken some work to secure user/patient representation on their local Steering Group. However, to date, some local projects have not yet secured a 'patient representative' on their TCAT Steering Group. Success is mixed and limited by:

- Capacity and time to prioritise this is limited, with some projects still in the early stages of implementation
- Ability of individual to commit and attend regularly (related to condition and wellness)
- Limited mutual understanding of role and language used

Where user/patient representation has been secured and deemed locally to be "working well" the context for this appears to be related to:

- The project already being implemented within a strong culture of involvement and developing co-production practices
- Developing relationships and representation from wider user/patient individuals and groups – not always cancer-specific
- The user/patient representative having a clear understanding of their role and expected contribution

Maximising involvement and moving to influence

The Baseline Report stated that "The work to date to incorporate the patient voice has been slow to come on stream, 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". A year on, there is evidence of more patient representation within the programme. However, in moving forward, TCAT, should aim higher as the programme presents an opportunity to develop and share good practice in service user involvement and more importantly in facilitating influence.

The extent to which 'the patient voice' is part of TCAT was rated by wider stakeholders who were also asked about the added value of regional and national programme structures supporting this area.

A higher percentage of wider stakeholders consider the patient voice to be part of local projects (45%) to a great extent, than at regional (27%) and national level (24%).

Table 8: Extent to which the patient voice is part of TCAT at interim stage

	Nationally		Regionally		Locally	
	%	(n)	%	(n)	%	(n)
To a Great Extent	24	11	27	12	45	21
Somewhat	35	16	42	19	43	20
Very Little	7	3	7	3	9	4
Not at All	2	1	2	1	0	0
Don't know	33	15	22	10	4	2
		(n=46)		(n=45)		(n=47)

Wider stakeholders consider that:

- Regional structures have added value to the delivery of the programme aims through supporting the inclusion of the patient voice within the TCAT programme, 'to a great extent' (37%) or 'somewhat' (45%).
- The TCAT Programme Board has added value to the delivery of the programmes' aims, through ensuring the views of patients and their families are at the core of planning and delivery of the TCAT programme, 'to a great extent' (34%) or 'somewhat' (47%).

The above figures emphasise that the programme board should give more priority to enhancing the facilitation of 'the patient voice' within the structure of TCAT, as these 'scores' could be viewed as low, highlighting room for improvement at all levels of the programme.

To date this important aspect of the TCAT programme has not been adequately determined, resourced or assessed. Given the emphasis on this within the National cancer plan, TCAT provides important opportunity to devise a rigorous evaluation/research strand to add learning and evidence to assist all long term conditions.

The development and funding of a robust programme of work, focussing upon the influence of people affected by cancer in service design and delivery, is recommended. Edinburgh Napier University have worked with the CEP to determine areas of positive collaboration and would work with the group to enhance the robustness of evidence emerging from their work and ours.

IMPROVING HEALTH AND SOCIAL CARE DATA

In order to look at what practice works, for whom, and in what circumstances, the national evaluation worked to ensure that '*the who'* was monitored and recorded by all projects. This was done through determining key 'profile' characteristics of the people who are engaging with the projects.

A picture of the needs of patient living with a cancer diagnosis at end of treatment is also being developed by the work of the TCAT programme. In addition to helping practitioners to "tailor" care and support to address identified needs, it "also gives a valuable source of information for research purposes and local service planning and commissioning"[22]. The aggregated data gathered from TCAT provides a valuable opportunity to understand the needs of people after treatment for cancer. In the future there will be potential to link this set to other Macmillan and national data sets.

The following sub-section presents a description and interim analysis, where appropriate, of data provided to the National Evaluation Team by nine local Phase 1 Projects[23]. It focuses only upon people who engaged in the TCAT arm of projects – that is people at the end of treatment.

TCAT Participants

Type of cancer– data from 9 projects

Overall half the local projects (13) include people affected by any type of cancer and a quarter (6) target a set group of cancers types. For some coverage was determined from the start of the project, for others 'additional' cancer types have been included during the implementation phase. One project does not focus upon a cancer type, but on a specific form of treatment for cancer – pelvic radiotherapy. Only one local project specified an age group for their work. This is North & South Lanarkshire Council (Phase 2) who plan to target people under 50. The national project is for teenagers and young adults affected by cancer.

Due to the targeting of single cancer types by projects, at this interim stage, 57% of the TCAT population is made up of people affected by only two cancer types (prostate and lung) and 86% overall by only 4 cancer types (prostate, lung, breast and colorectal).

Table 9: Cancer Type

	%	n
Prostate	31.2	267
Lung	25.7	220
Breast	16.6	142
Colorectal	12.4	106
Melanoma	9.0	77
Gynaecological	3.2	27
Other	2.0	17
	100.0	856

As a result of the targeting of gender specific cancers, four projects are engaging either only with men (2 prostate projects) or women (2 breast cancer projects). For the other five projects, the gender profile varies, but can still be seen to relate to gender specific cancer diagnosis. For example, the predominance of women within NHS Lothian project (with over 55% having breast or gynaecological cancer) and of men in NHS Tayside where a fifth (22% have prostate cancer). For the only 'all cancer' project (NHS Borders) 60% of participants were male and 40% female.

All TCAT projects are engaging predominantly with people with a primary stage of cancer. Where data is known, only two projects have a proportion (between 12% and 20%) of people with a secondary diagnosis.

Age– data from 9 projects

The age of local project participants varies between projects, however a large majority (79%) are aged 60 or over. Less than one in ten is aged under 50. Over three-quarters (79%) are aged 60 or over and those aged 80 or over make up nearly 18% of the interim TCAT population.

Table 10: Age

Age	%	(n)
under 50	7.5	65
50 to 59 years	13.9	120
60 to 69 years	30.4	263
70 to 79 years	30.5	264
80 and over years	17.7	153
		865

Ethnicity - data from 7 projects

TCAT is engaging with an overwhelmingly white Scottish/British population because of the nation's overall ethnicity profile. Those of other ethnic groups or backgrounds among the projects make up a very small percentage (less than 2%). (NB for some projects this data was not comprehensively collected).

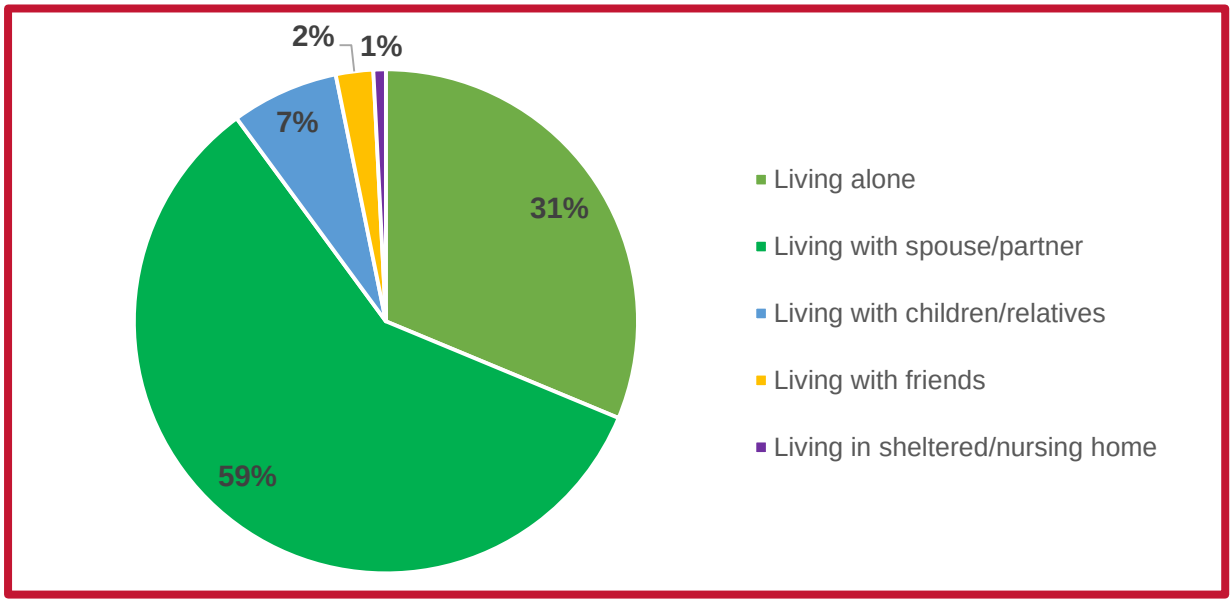
Economic Activity Status – data from 6 projects

TCAT to date has engaged with a predominantly retired population (77%), and within each project the majority of people are retired (ranges from 92% in NHS Fife Lung to 46% in NHS Lothian Phase 1).

Living Situation - data from 6 projects

Most of the people engaged with TCAT to date live with their spouse or partner (between 48% and 77%). However, a significant percentage of people live by themselves (between 14% and 47%).

Table 11: Living situation



Performance status – data from 5 projects

The performance status of TCAT participants was measured using the ECOG performance measure[24] . This was an attempt to quantify the person's physical abilities and level of independence post treatment.

The best supportive care project for advanced lung cancer patients in NHS Fife is involved predictably with a 'less well' population. Within this project over a third were 'scored' capable of only limited self-care and were confined to bed or chair more than 50% of waking hours. Among the other projects, fewer than 6% had such a low performance score.

Concerns identified to date

Data is available for 405 people in 6 projects who completed a Concerns Checklist at the end of their treatment. Of these, almost three-quarters (298) had one or more concern at this time, collectively citing a total of 1,492 concerns.

Table 12: Concerns identified after treatment

Category of Concern	As a % of all people assessed	No. of people with a concern of this type
Physical	62.7	254
Emotional	27.2	110
Practical	20.2	82
Lifestyle or Information	17.3	70
Family, Relationship	8.6	35
Spiritual or Religious	3.7	15
		(n=405)

The 10 most frequently identified concerns are shown in the table below.

Table 13: Ten most frequently identified concerns after treatment

Concern identified	%	(n)
Tired/exhausted or fatigued	24.9	101
Hot flushes/sweating	19.0	77
Worry, fear or anxiety	17.8	72
Sleep problems/nightmares	16.3	66
Getting around/walking	14.3	58
Pain	14.1	57
Eating or appetite	12.8	52
Memory or concentration	12.6	51
Dry, itchy or sore skin	12.1	49
Tingling in hands/feet	11.1	45

All but one of the top 10 were physical concerns. The third most frequently cited concern was the emotional concern of worry, fear or anxiety. Within the category of practical concerns the most commonly identified was ‘travel and insurance’ (23 people) followed by ‘work or education’ (21 people). The most commonly cited lifestyle concerns were ‘physical activity’ (32 people) and ‘nutrition’ (20 people).

It is recommended that data from TCAT on ‘identified concerns’ at the end of treatment be further examined and used to inform new models of care.

UNDERSTANDING AND IMPROVING RESOURCE USE

TCAT aims to contribute an improved understanding of resource use across health and social care. Using a number of local projects as detailed case studies it is asking of them "To what extent does the programme provide more cost effective solutions and a more appropriate use of resources than current practice. The work being carried out over the next 18 months by Edinburgh Napier University is summarised below and makes a significant contribution to the National health and Wellbeing Outcome Number 9: Resources are used effectively and efficiently in the provision of health and social care services.

- Cost utility analysis examining impact on quality of life and costs of TCAT follow up in NHS Ayrshire and Arran
- Comparing costs and outcomes between old and new follow up pathways in NHS Fife Dermatology and NHS Lothian Wester Haven
- Cost benefit analysis examining potential benefit as gains in Fact-L ratings and the cost to achieve these – NHS Lanarkshire
- Investigating reductions in unplanned admissions, in-patient investigations and outpatient appointments as a result of development of a Best Supportive Pathway for palliative lung patients in NHS Fife

NHS Fife (Lung Cancer)

Lung Cancer Palliative Care TCAT Project

Aim to test change in the palliative model of care to evaluate if earlier, more proactive and responsive specialist palliative care assessment and ongoing community follow up results in patients with advanced lung cancer and their carers feeling more supported, promotes self-management, reduces secondary care follow up, reduces unplanned admissions to acute beds and improves integration of care between health, social care and the third sector.

Four TCAT projects who are developing new community based models of follow up are also working with the evaluation team to determine the best health economic evaluation tool to use to determine the extent to which they provide cost effective solutions. This will include, for example, interrogating data on formal referrals made from a community base back into the NHS as a result of an HNA.

Funded by the Scottish Government (May 2015)[25], a number of TCAT related initiatives across Scotland are working to further develop protocols for patients with cancer to reduce medical led follow up appointments. Although related to TCAT, the evaluation team have no role in these projects or their evaluation. Findings from this work will complement the TCAT– led health economic evaluations by Edinburgh Napier University.

POSITIVE PROSPECTS FOR SUSTAINABILITY

The TCAT Programme was not designed solely to fund 25 individual Macmillan projects to address local needs, but was structured as an overall programme of sustainable transformative change.

There is consensus that 'success' would be TCAT components becoming "*business as usual*", *"embedded into routine practice*" and part of the *"core business*" of health and social care practitioners and policy makers.

While some wider and core stakeholders and local projects questioned the high expectations the use of the term 'transforming' can evoke, there is evidence that three years into a five year programme, appropriate foundations for sustainability have been put in place. There is, however, a need for dedicated effort to strengthen the 'building blocks' of sustainability.

Crucial 'building blocks' for capitalising on the foundation work and maximising sustainability and roll of TCAT activity are leadership, ownership, commitment and an ability to influence attitudes, behaviours and priorities**.**

Leadership, ownership and commitment

As in the Baseline Report, at this interim stage, projects were found to be highly committed to and positive about their local TCAT service, and there is evidence of local teams working to foster and sustain local commitment and enthusiasm for TCAT. This may be a result of the bottom up approach to service delivery taken by the programme. The ground level origination of bids and projects has ensured the work is 'owned' locally and this will be an important factor for roll out and future sustainability. Local ownership of projects has built a positive platform for sustainability complimented by regional network involvement and responsibility. At a local level there are new networks and connections which will need to be strengthened to ensure the ongoing development and sustainability beyond the life of TCAT.

Across the projects there are four different project leads who submitted the application and/or is leading on the project locally:

- 9 by nurses (7 are Phase 1 projects)
- 7 by hospital consultants (4 are Phase 1 projects)
- 3 by GPs (all are Phase 2 projects)
- 7 by Local Authority Officers - Service Heads or Managers (all are Phase 2 projects)

Influencing attitudes, behaviours and priorities related to care after treatment: cultural change

TCAT can be seen as part of a wider cultural and policy shift within health and social care provision in Scotland, which emphasises reducing episodes of secondary care, moving care closer to home and the promotion and support of self-management.

As such the programme prioritised sustaining local practice and embedding change within the criteria for local projects – asking them to raise awareness of the importance of care after treatment services and support and activities to influencing attitudes, behaviours and priorities.

Over a third (36%) of wider stakeholders think that the TCAT programme is having a direct impact on increasing awareness and acceptance of the importance of care after treatment 'to a great extent' and 55% consider the impact as 'somewhat'.

Among wider stakeholders, 28% think that the TCAT programme is having a direct impact on influencing attitudes, behaviours and priorities related to aftercare 'to a great extent' and 49% think 'somewhat'.

Evaluation work has not been directed at 'quantifying' changing levels of awareness or attitude, but qualitative analysis of interviews, surveys and group discussions found a positive narrative of TCAT's impact and provided examples of new relationships being forged that will further support sustainability.

The overall structure of the TCAT programme puts the onus for maximising sustainability and/or roll out on all three levels of the structure – national, regional and local. This multi-layered approach to leadership offers great potential for maximising sustainability, for example, through the role of Macmillan Cancer Support and the added value of being part of a national programme. However, it is not without its risks, which were found to include:

- the extent to which TCAT roles and remits are understood
- communication issues

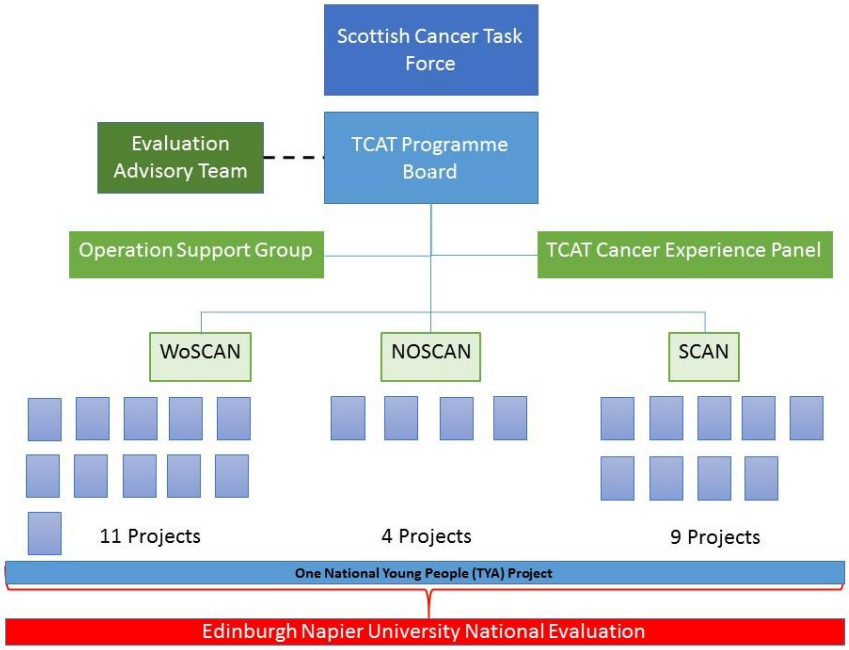
Understanding roles and remits

When looking at the design and operationalisation of the TCAT programme, there are two recurring themes relevant to the given roles and remits of the various stakeholders:

1. The extent to which various remits are understood
2. Views on the extent to which these roles are 'adding value' to the programme.

The structure of the programme is illustrated below and details of remits are provided in Appendix One.

Roles within the programme



A lower level of understanding of the regional networks' remit and role overall and, in particular, among TCAT projects that are not within the NHS (primarily Phase 2 projects), was found within focus group discussions.

> *"It's just the structures are complex and not easily understood, particularly where you've got the government bit, and you've got the TCAT bit and you've got the networks and actually trying to work out where the lines are is not easy, wasn't easy."*(Project)

The survey of wider stakeholders gathered views on what would enhance the role of various parts of the programme structure. Respondents suggested that, nationally and regionally, more work needed to be done to develop a better operational understanding of the implementation and delivery issues being faced and addressed by local projects. This *"coalface"* understanding would also enhance the Programme Board's role to provide support when things were not going *"smoothly*". A lack of mutual understanding leads some projects to consider the regional structure as an added layer of bureaucracy.

At all levels of the TCAT structure there is a need for better understanding of roles and responsibilities. This would be aided by (a) the dissemination of a clear 'vision' for TCAT (b) stronger communication channels and (c) work to increase knowledge and understanding of the working practices and environments of all involved stakeholders.

Issues of communication

The second area in which issues relevant to sustainability have arisen from the design of the programme is also in two parts – firstly communication channels and secondly the resulting clarity and consistency of strategic and operational 'messages'.

For some the actual 'machinery' of TCAT, the three layered structure and 25 individual operational 'sites', has resulted in both strategic and operational messages being lost in translation. One wider stakeholder commented *"there are a lot of subgroups which means that whilst the programme board has oversight of issues/progress, the detail is often lacking. A number of conversations take place out with the Board at a sub group level and I believe this means some people have more knowledge of the programme than others and perhaps more ability to influence".*

There is also a perception among projects and stakeholders of duplication of communication channels for clear advice. At times, this has resulted in confused or misunderstood messages of procedure or programme priority.

> *"There is a lot of muddying of the waters"* (Core Stakeholder)

Of the wider stakeholders who suggested ways to enhance the role of the national and regional layers of the TCAT structure, many identified that what was required was communication that is *"clear", "brief*" and *"comprehensive".*

A related issue is the reported 'tone' of some communications, which may be attributed partially to the multiple channels and lack of resulting clarity. Examples of "*difficult conversations"* and different parts of the structure "*cutting across each other";* and negatively associated words such as *"big stick to beat us", "dictatorial" and "sanctioning"* were also recorded.

In response to the question 'what is required to enhance the role of the regional structures' one wider stakeholder replied that Regional Stakeholders needed to be "*less authoritative and more integrative to the project delivery. [to] Work with the team to deliver [and] Listen"*.

The difficulties in conveying succinctly and precisely the aims, principles and activities of such a large transformational programme to a diverse audience are significant. For example, the Baseline Report found a variety of meanings associated even with the term "after care" among stakeholders and projects and a year on this is still a design-created risk that has not been managed, in part, by clear communications.

> *"I do think that at times the national team complicate it too much, the message is getting very complicated and it does put people off. I see clinicians and managers, when you try and talk about the whole message of TCAT, start to glaze over. For me, I think the message needs to be*

focused a bit. I wonder whether they're trying to do too much" (Core stakeholder)

Wider stakeholders were asked to what extent has the TCAT Programme Board added value to the delivery of the programmes by providing clear direction/communication about the programme for working groups and wider stakeholders across Scotland. A third (32%) of respondents thought that they did this to a great extent and 58% only somewhat.

Table 14: Programme Board adding value to communication and direction

	Phase 1 stakeholders only	
	%	(n)
To a Great Extent	32	20
Somewhat	58	26
Very Little	2	1
Not at All	0	0
Don't know	8	5
		(n=52)

Issues of capacity

The local capacity for administration, planning, evaluation, and, in some cases, project management, has impacted on the implementation of TCAT. For a number of projects the need to develop a new service while carrying out their normal jobs was challenging and for some, not possible. A lack of capacity to dedicate to a TCAT project prior to formal roles being in post could delay the operational start date - by many months in some cases:

"it's almost that chicken and egg situation, because what we really needed was we needed to pre project manage, but actually we didn't have that capacity and then of course what we desperately needed was a project team in…but we couldn't get the project in team in until we had done all the paperwork" (Project)

"I think the notion that you're going to have 6 – 9 months kind of planning time to sort of focus on your TCAT work strikes me as incredibly naive about the realities of what we are currently working with" (Project)

This lack of dedicated capacity was further exacerbated, particularly for Phase 2 projects, by the local organisational demands made by Scottish Health and Social

Care Integration. Staff changes and turnover within Local Authorities has also delayed the implementation of some local projects.

Being part of a national programme and the role of Macmillan

Although only 27% of wider stakeholders reported that they feel part of a national programme 'to a great extent', all local projects and core stakeholders feel part of the national TCAT programme and all reported many benefits from this.

The key benefits or added value of being part of TCAT were described as including:

- The availability of money from Macmillan to implement local priorities
- Association with a well-regarded, reputable organisations with expertise in cancer
- 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
- Availability of advice and support from different parts of the structure
- Macmillan having a strategic vision for care after treatment and providing leadership
- Providing a framework for coming together to learn and develop practices
- Access to training (not TCAT specific)

ENSURING AND ENHANCING THE EVIDENCE

Limitations to current evaluation contract

The preparation of the Interim Report has illustrated that the limitations of the current national evaluation are related to:

- Coverage
- Capacity

The national evaluation was commissioned as an overall programme evaluation and, as such, the expectation was that "*a substantial component of the evaluation is to support local self-evaluation of the projects to help make the case at a local level about the value and impact of their work in order to secure sustainability*"[26]. There was no expectation at the time of commissioning for the programme evaluation to report at project level but the commissioners stated that the wanted to *"align the project self-evaluations with the programme evaluation and provide the necessary support to projects to gather the data they will require at the local level*"[27].

In order to align self-evaluations that local projects would devise and conduct, to the overall programme evaluation, an early decision was taken by the evaluation team and advisory group to focus available evaluation capacity on Core Data (i.e. number and profile of TCAT participants) and only the predominant Recovery Package intervention being tested within TCAT – holistic needs assessment (HNA) (i.e. the processes and actions resulting from the assessment). Both have been reported on in this Interim Report.

As a result of this focus, at present there is no dedicated national evaluation work being carried out in these areas.

- The impact of assessment at the end of treatment on self-management
- Care planning content and outcomes
- End of Treatment Summaries
- Health and Wellbeing Events
- Information provision (service mapping and service directories)

Therefore, the quality and content of a national evaluation of these components is totally reliant on the quality of future local evaluation work and the more generic 'higher' level monitoring and activity data submitted to the national evaluation team. High level activity data and a synthesis of local reports alone will not do justice to the overall programme, nor to the sustainability/roll out potential of these components.

The issue of capacity and coverage by the national evaluation team is compounded by the limited capacity of local projects for evaluation planning and activity. To date, the Evaluation Team has provided a significant level of support and advice around

evaluation design, content and implementation. This has been done via intensive one to one assistance, the facilitation of three evaluation workshops and the collation and management of local data submissions. This support role is under resourced, inequitable and unsustainable. This was crystallised by a core stakeholder who commented:

> *"We really valued the, you know, the Napier team working with individual projects because they gave these individual projects the support they often required. And it maybe wasn't, you know, just about evaluation. …. they have encouraged and facilitated and helped the team, the individual project teams along with their day to day work, never mind, separate, entirely separate from the evaluation. I think it was a big ask of the evaluation team to do that, get that so heavily involved. And therefore you have to spread yourself more thinly and I think it's a lesson that we need to learn".* (Core stakeholder)

Recommendations to enhance the national evaluation

It is recommended that to provide rigorous evaluation and robust results there is particular added value in the national evaluation being more proactively involved in local evaluation work for an agreed number of projects. For others the national evaluation would still answer queries and provide support and advice when required to ensure the collection of the national data.

In addition, there is need for early agreement for a rolling programme of reporting of findings and learning. As the findings from local evaluations come on-stream it will be important to continue to distil and disseminate key learning points. Action is also required to maximise the opportunity to determine key messages and outputs from the evaluation which have national and international impact and significance. Audit Scotland recommended that there is a need to ensure that learning from new models of care is shared effectively to help the pace of change. With that in mind, Edinburgh Napier University are recommending a series of TCAT Reporting Bulletins replaces the planned Final report in late 2018. This will help ensure key learning is appropriately targeted, timely and disseminated widely.

The following new reporting and dissemination framework is recommended.

In 2016:

- TCAT and the Patient Voice: From Involvement to Influence No. 1
- TCAT and cost effectiveness No. 1 : evidence from 5 projects
- TCAT – Hospital based /CNS use of the Concerns Checklist/HNA – findings and learning from 7 completed projects.

And during 2017/2018 the following bulletins:

- TCAT and the Patient Voice: From Involvement to Influence No. 2
- TCAT and cost effectiveness No 2: evidence from 4 community based projects
- TCAT – Community Based projects: Findings and Learning
- TCAT: Service Integration and Co-ordination
- A set number of special interest/project /theme reports as agreed in new contract
- Final report on programme overall

LESSONS AND RECOMMENDATIONS

Interim lessons

At the interim stage of a five year programme, TCAT's role and reach is significant. Over the next two years its contribution to the care provided to people affected by cancer specifically and the enhancement of health and social care provision in general, will increase.

> TCAT has resonance in Scotland and further developments should link themselves to this 'brand'.

Macmillan Cancer Support acknowledge that "large scale transformative programmes of work take longer to deliver and even longer to see the full results"[28]. While there are few 'quick wins' in cultural and transformational change, the interim findings have identified 'early impact' and demonstrated the contribution TCAT can make to key strategies, policies and local operational decisions across Scotland.

> There is a need to review and re-focus the planned evaluation activity to ensure a robust outcomes-focused evidence base that secures TCAT's role in making a significant contribution to current issues faced by providers and the national strategic priorities of health and social care in Scotland today.

The evaluation has found that there is value for local projects in developing new models of care within a 'national programme' and that the reputation and expertise of the funder is required and appreciated by projects.

> High profile programmes of 'transformational change' result in equally high expectations, and programme leads need to strategically and operationally manage these.

Whilst a range of design and structure issues and implementation related challenges have been identified, there was consensus that the structure had the anticipated potential to contribute to TCAT's principles of: improving practice outcomes and experiences; enhancing service integration and coordination; and maximising sustainability and roll out. The phased approach and iterative build-up of the support structures for the programme has, however, given rise to a number of delivery delays and challenges.

> The programme has engendered and maintained strong commitment from stakeholders. However, implementation in some areas has been

slow and dominated by local operational issues, to the detriment of the overall strategic management of the transformational vision.

A key lesson is the need for early support/capacity at the development/design stages of projects to better develop operational plans at the expression of interest stage. In addition, limited evaluation capacity and resource at a local level will undermine the value of the growing evidence base.

At all levels of the TCAT structure there is a need for better understanding of roles and responsibilities. This would be aided by (a) the dissemination of a clear 'vision' for TCAT (b) stronger communication channels and (c) work to increase knowledge and understanding of the working practices and environments of all involved stakeholders.

TCAT can be viewed as a catalyst for partnership working and the development of improved cancer service integration/coordination, which should be used as demonstration sites to inform other long term conditions. At a local level, there are new networks and connections which will strengthen the ongoing development and sustainability beyond the life of TCAT.

For TCAT to successfully enhance service integration and coordination of care after treatment services and support, it will have to maximise the opportunities the programme has provided and work to ensure that developing partnerships are not short lived or merely TCAT specific.

The way in which the Cancer Networks can add value to service integration and co-ordination should be given continued priority.

TCAT provides a valuable opportunity to explore and develop innovative approaches to engaging people with experience of cancer in the design and delivery of services. Given the emphasis on this within the national cancer plan, there is a parallel need to further promote and sustain TCAT's aspirational moves from individual patient representation and facilitate more innovative approaches to increasing the influence of patients, carers and the public. However, to date this important aspect of the TCAT programme has not been adequately determined, resourced or assessed.

Moving forward TCAT, at all levels, should aim higher in relation to being an exemplar of patient influence in a transformative programme of change. This aspect of the programme requires review and targeted implementation and evaluation.

Crucial ‘building blocks’ for capitalising on the foundation work and maximising sustainability and roll out of TCAT activity are leadership, ownership, commitment and an ability to influence attitudes, behaviours and priorities. The structure of TCAT supports the principle and aim of sustainability to be achieved at national, regional and local levels. Local ownership of projects has built a positive platform for sustainability complemented by regional network involvement and responsibility.

There is a need for dedicated effort to strengthen the ’building blocks’ of sustainability identified in this report. In addition, the actual vision of sustainability and roll out (known as Phase 3 of the TCAT Programme) needs to be voiced with clarity as early as possible to enable the multi-layered leadership of the programme to maintain interest.

For a programme to maximise sustainability, it is important for leaders to concentrate on not losing the momentum as TCAT moves into the end of its ‘formal’ programme stage.

Interim recommendations

1. There is particular added value in the national evaluation being more proactively involved in local evaluation work for an agreed number of projects.
2. In order to better understand new models and approaches to assessment and care planning and how they impact on costs and outcomes, future evaluation work should examine differences across the local projects as a means of ‘fine testing’. This will help to answer questions around the impact of the setting and person delivering the assessment.
3. It is recommended that data from TCAT on ‘identified concerns’ at the end of treatment be further examined and used to inform new models of care.
4. That there is a new reporting and dissemination strategy to enhance implementation of evaluation findings nationally, regionally and locally.
5. The second phase of evaluation should focus on the way in which organisations work to better integrate and coordinate services in order to improve outcomes and experiences for patients/service users.
6. The development and funding of a robust programme of work, focussing upon the influence of people affected by cancer in service design and delivery.

APPENDIX ONE: Remits

Employed by Macmillan Cancer Support, TCAT has a full time National Programme Manager. Nationally, TCAT is overseen and governed by a Programme Board, established in 2013 to provide national leadership in the shaping and delivery of the partnership. It is made up of over 20 members, representing Scottish health boards, local authorities, the third sector and Macmillan. They meet quarterly and their remit is shown in the box below.

Box: Remit of the Programme Board

- Shape the TCAT programme through the development and delivery of a Programme Implementation Plan
- Ensure the views of patients and their families are at the core of planning and delivery of the programme
- Implement the appropriate governance framework to support the successful delivery of the programme, including the creation of supporting posts.
- Develop and implement an appropriate mechanism to facilitate the selection and funding of test / evaluation pilots to deliver programme objectives.
- Have oversight and mitigate programme delivery risks
- Monitor and evaluate programme performance
- Provide clear direction / communication for both associated sub/working groups and wider stakeholders across Scotland
- Report performance to Scottish Cancer Taskforce
- Ensure effective and appropriate linkage to other related national programmes

The Regional Cancer Networks (NOSCAN, SCAN and WoSCAN)

TCAT funding was provided to the Networks to cover clinical release time and project administration. TCAT Clinical Leads and Project Managers have been appointed in each region and are tasked overall with "supporting and driving the TCAT programme forward"[3] and specifically with supporting:

- local projects
- wider clinical engagement
- the wider roll out of service improvements across the region

[3] TCAT Operational Guidance 11 July 2013

- the wider integration between health and social care

TCAT Operational Group

This working group of the Programme Manager and Network Clinical Leads and Project Managers acts on behalf of the National Board to provide support and oversight to the delivery of the programme.

Evaluation Advisory Group

To provide national advice on the shaping and delivery of the evaluation of individual TCAT development projects and the full TCAT programme

TCAT Cancer Experience Panel

The Panel was established "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"[4]. The programme employs a Service User Involvement Manager who is based at The Alliance[5].

Edinburgh Napier University

The overall evaluation aims to support the self-evaluation of the 25 TCAT 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.

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