

Transforming Care After Treatment Partnership, Integration and Co-ordination Johnston, L; Campbell, K Edinburgh Napier University

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Introduction

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

Edinburgh Napier University was commissioned by Macmillan Cancer Support in May 2014 to conduct a national evaluation of the TCAT programme. Each of the 25 local TCAT is producing a self-evaluation report. The results of the national programme evaluation have to date been presented in a Baseline Report (2016) and Interim Report (2017). In 2017 it was agreed that findings from the national evaluation would also be disseminated through a rolling programme of Evidence and Learning Bulletins on specific topics.

- Measurable Outcomes from TCAT
- TCAT and the Patient Voice: From Involvement to Influence
- Holistic Needs Assessment: Implications for Practice
- Impact of TCAT on partnership, integration and co-ordination
- Impact of TCAT on influencing attitudes, behaviours and priorities related to after care
- Mechanisms of HNA and Care Planning A Realistic Evaluation
- Final 'wrap up' report on the national evaluation

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

Sources

This Bulletin has been informed by the ongoing analysis of data from the national evaluation work strands.

For this bulletin we have drawn the following sources:

- Pre implementation (n = 11) and post implementation (n = 7) focus group discussions with members of the Steering Groups of local projects.
- Interviews with TCAT Core Stakeholders (n=9). These are representatives of the programme's national and regional governance structures.
- An online survey of wider stakeholders (defined as local project's Steering Group members, regional and national stakeholders) conducted in 2015 (n = 195/responses = 73) and repeated in 2016 (n =371/responses = 134) and 2017 (n = 371/responses = 106).
- Review and synthesis of the local evaluation reports of 17 local TCAT projects.
- Extraction and analysis, where valid, of patient survey responses to the questions relevant to their experience of integration and coordination.

These are presented in detail in the <u>Baseline</u> and <u>Interim</u> reports and accompanying Technical Appendix (on request <u>TCAT@napier.ac.uk</u>).

Purpose and Content

This Bulletin presents the evaluation findings and learning to date from a national evaluative perspective. By building on the findings presented in the Baseline and Interim report, this Bulletin sets out what is known about the <u>impact</u> of TCAT to date by answering a key national evaluation question:

To what extent has the programme enhanced service integration and coordination of after care services and support?

The Bulletin highlights progress in this key priority area and disseminates the learning.

In presenting the evaluation findings and related learning, a distinction is made between 'partnership working' defined as engagement, 'getting round the table' and/or consultation processes and actual service integration and service coordination.

The bulletin begins by presenting evaluation of the impact the programme design has had on supporting and encouraging partnership working. It then focusses in turn on the following aspects of service integration and coordination:

- Raising awareness of services and support
- Developing referral routes to services and support
- Cross sector partners in project delivery
- Pathway development to encompass after care.

Background /Context

TCAT was devised and implemented during a period of refocussing and restructuring of Scotland's health and social care services to enhance partnership working and integrated and coordinated provision.

The Christie Commission on the 'Future delivery of Public Services (2011)ⁱ believed that 'rising demand and cost pressures compounds the impact of Scotland's tightening budgets' and included a recommendation to concentrate the efforts of all services on delivering integrated services that delivered results. This recommendation and others were included in the Scottish Government's strategic vision for health care services 2020 Visionⁱⁱ envisioning a health care system fully integrated with social care.

In 2014 the Scottish Government signalled a move from strategic encouragement towards legislative duty and guidance with the 'Public Bodies (Joint Working) (Scotland) Act 2014ⁱⁱⁱ. 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^{iv}.

Effective partnership working, service integration and enhanced coordination between supporting agencies is a priority aim of public sector strategic reform and developing operational practice across health and social care services in Scotland.

Whilst TCAT targeted people affected by cancer, its relevance and contribution to wider public sector priorities and strategies to enhance integration was prioritised in the programme. This was done by embedding a focus on enhancing integration, coordination and partnership working into the Programme's aims, structures (see Figure 1) and implementation processes.

Figure 1: Structure of TCAT



A key strategic and operational aim of TCAT is to 'support and encourage the development of integrated health and social care, built around the needs of people with cancer'.^v

TCAT was operationalised via the commissioning and funding of 25 local projects, tasked with the development, testing and evaluation of new models of after care service delivery and practice. Each project was encouraged to meet set 'partnership involvement criteria' which included demonstrable engagement across the care sectors of acute and primary care NHS, social care and 3rd sector organisations. In addition, commissioned projects were asked to articulate in their proposals and evaluations how health and social care integration had been progressed via their project.

PARTNERSHIP WORKING

Partnership working by design

National and regional partnerships

TCAT established a partnership programme at a national level between the Scottish Government, Macmillan Cancer Support, NHS Scotland, local authorities and third sector organisations. This is supported by a memorandum of understanding between the Scottish Government and Macmillan Cancer Support and overseen by a multi-sector TCAT Programme Board.

To support this national partnership, regional TCAT Implementation Groups, within Scotland's three Cancer Networks (NOSCAN, SCAN and WoSCAN), were established. A key remit of these groups was 'to support wider integration between health and social care'^{vi}.

The national evaluation asked wider stakeholders for their views on the extent to which this regional role was adding value to improving integration between health and social care.

In 2015, 24% (n = 8) viewed the networks role as adding value to a great extent in this area, with 53% (n=18) responding 'somewhat'. By 2017, those reporting this role as adding value to a great extent had increased to 31% (n = 17).

The inclusion of Phase 2 local project representatives onto the Regional TCAT Implementation Groups, increased representation of local authorities at this level. Eleven Scottish local authorities are involved directly in TCAT.

However, across the formal structures of TCAT, the programme nationally and regionally remains numerically dominated by NHS representatives. There is a need to redress this balance and as the formal programme comes to an end there is also an imperative to determine the role of the Cancer Networks in furthering the integration agenda.

Overall the prioritisation of partnership working by TCAT, resulted in the programme being viewed as providing a tangible, funded opportunity for national, regional and local stakeholders to pursue closer working relationships and consider their individual roles in more joined up services. As such, TCAT is having a direct, positive impact on increasing partnership working in the field of cancer care.

The role of the third sector

In relation to the engagement of third sector organisations within the design of TCAT, a gap at <u>national and regional</u> level was identified from the start by core and wider stakeholders. The Baseline Report identified a level of concern and to some extent 'unease' as to the level of engagement and participation to date with the third sector. This was particularly true in relation to the involvement of other cancer charities in Scotland.

"But I think we could do better at getting a shared agenda there, so we're speaking from a third sector platform". (core stakeholder)

"but it doesn't leave a lot of scope for smaller organisations." (local project)

""And, the other charities are not at the table. And, that is just because this is a Macmillan funded project but there are a number of the other smaller charities and the tumour specific charities, who've got good ideas around transforming care as well" (core stakeholder) In 2015, wider stakeholders in the longitudinal survey identified the third sector as an agency or organisation they considered important to TCAT that was not currently involved in the programme or local project. This was not evident in the responses to the 2016 and 2017 surveys.

At a national level a representative of the Cancer Coalition is a member of the Programme Board and the appointed TCAT Service User Involvement Manager, was based at THE ALLIANCE, 'the national third sector intermediary for a range of health and social care organisations'^{vii}.

At a <u>local level</u> there was evidence of early consultation with 'third sector' organisations. In project proposals, third sector links were being reported, although these were predominately with Maggie's Centres, with few if any other local voluntary sector organisations being noted. A number of local projects consulted with cancer specific charities and two local projects had not been in contact with any third sector representatives in preparing their expression of interest.

The Baseline Report identified that the phased commissioning of secondary care based projects, followed by community led projects a year or so later, may have impacted negatively on initial cross sector relationships and well developed joint local TCAT proposals.

An example of both partnership across sectors and service integration is the Phase 2 project in the Scottish Borders. It 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.

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.

The role of primary care in TCAT

Another area of mixed success for the engagement of partners in TCAT is that of the role of primary care organisations and professionals in the programme. A Macmillan GP sits on the Programme Board and three primary care led projects were commissioned.

There is evidence of some projects developing closer working relationships with GPs and practices in their area. For example the Midlothian Living Well After Cancer project established close links with the GP cluster and all 12 Midlothian GP Practices have undertaken the Macmillan Cancer Care GP Toolkit. Each prioritised module 4 (cancer care reviews) in order to promote TCAT to their patients.

The Phase 2 project based at Wester Hailes, Lothian prioritised raising awareness of their 'active inclusion protocol' which formalised invitations to attend for a holistic needs assessment from GPs to patients at the end of their active treatment. As a result of this the TCAT project received a higher levels of GP referrals into the project.

However, others reflected on the challenges of securing a primary care representative and/or lack of attendance at steering group meetings, receiving limited response to requests to engage and subsequent difficulties in developing hoped for referral.

Developing and strengthening cross sector partnership working

The national evaluation has found evidence of enhanced partnership working at a local level across health, social care and third sectors as a result of TCAT. In addition it is evident that for those involved, TCAT provided an impetus and focus to develop working relationships across traditional sector boundaries and to strengthen existing partnerships, focused on the care after treatment of people affected by cancer. This was done via the provision of funding, a shared, tangible focus on improving the after care of people affected by cancer and the actual piloting and testing of various models of care that prioritised integration and coordination.

Evidence of formal partnership working includes a joint bid from two local authorities (North and South Lanarkshire) and across Ayrshire public and private sector organisations working together to deliver the TCAT Employability Project. 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).

Local collaborations, the development of service links and networks and the value of multi-agency working features predominantly when wider stakeholders were asked to give one example of what within the TCAT programme they thought was working really well. For example:

"the teamwork and collaboration with other healthcare professionals but also with social care colleagues has been hugely constructive and this in itself is a positive outcome" (wider stakeholder)

"great partnership working to the benefit of the client" (wider stakeholder)

"people are genuinely talking!" (wider stakeholder)

"barriers are being broken down and bridges built between health, social care and third sector" (wider stakeholder)

All 17 local evaluation reports reflect positively on the impact TCAT has had on local partnership working. From the focus group discussions with projects and local

evaluation reports, impediments to service integration and coordination included – IT incompatibility, capacity in all sectors for TCAT in a period of structural change and resource restrictions across the public sector.

TCAT has however played an important wider role, that of encouraging and supporting new and existing partnerships. During the implementation of local projects, TCAT and its aims were variously described by wider stakeholders and focus group participants as a "driver", "instigator", "catalyst" and "enabler" of partnership working.

Of note in the analysis of the wider stakeholder survey was the emphasis placed by respondents on the importance of continuing these partnerships, post TCAT. Increased and maintained joint working across all sectors was suggested by respondents (n = 5 in 2015, 2016 and 2017), when asked "what is required to enhance the sustainability and/or roll out of elements of the TCAT programme?" This was second only to a need for evidence of effect.

SERVICE INTEGRATION AND COORDINATION

Raising awareness of services and support

A key way in which TCAT has enhanced service integration and coordination between local service providers has been through raising awareness among professionals in health, social care and the third sector of locally available sources of after care services and support. A higher level of understanding of ways and means of supporting people affected by cancer after treatment was reported by projects and the value of this acknowledged.

"and I'm actually sure that many more people (nurses) are aware of community sources of support that they didn't have. So I think that's been a big plus for me". (local project)

"I have learned a great deal about resources available to patients and their families within their community" (wider stakeholder)

"secondary care staff are much more aware of community sources of support" (wider stakeholder)

"I think that (now) we've got a great understanding of what services are out there, and help that's out there. We had no concept that all that was there" (local project)

Two projects held pre-launch stakeholder information or away days. Their local evaluation reports reflect positively on these events as a way of increasing understanding of their work among relevant stakeholders but also crucially, in increasing their own knowledge of prospective 'partners' in their locality.

The increased awareness of sources of support for people after treatment has been consolidated by a number of local projects. For example in Ayr, the Scottish Borders, Fife and Tayside work continues to populate and update an official service directory for use by health and social care professionals. Other local projects also worked to 'map' the relevant services in their area to inform and improve referral and signposting practice.

"Because we actually built a service, a local service information directory, you know, of all the services that are out there. And that got bigger, and bigger, and bigger. So actually, we all know all the things that are - the dog walking, the exercise things, the whole, you know, we built that up. And that's something that wasn't really all that well known before". (local project)

Feedback about how participants (patients and service users) viewed the TCAT project in relation to service coordination and integration was available from 7 projects. These were the Phase 1 projects in NHS Tayside (n = 85); NHS Borders (n = 9); NHS Forth Valley (n = 29) and the Phase 2 projects in NHS Lanarkshire (n = 77) and NHS Lothian/Westerhaven (n = 13).

For Greater Glasgow /Stobhill Phase 1 and the Phase 2 projects in Fife Council and Renfrewshire Health and Social Care Partnership comparative data was available. Sample sizes are shown in Table 1.

Table 1: Number of patients responding to baseline and feedback surveys

Project	Baseline/pre TCAT (n)	Post TCAT/Feedback (n)
GGC/Stobhill	34	46
Fife Phase 2	57	32
Renfrewshire Phase 2	62	47

Participants were asked the extent to which they agreed with two statements when thinking about the TCAT service they had experienced.

- I was passed around from person to person without getting the support I need (Table 2)
- 2. It helped me get other services and help to put everything together (Table 3)



Table 2: I was passed around from person to person without getting the supportI need: percentage strongly disagreeing pre and post TCAT service

Table 3: It helped me get other services and help to put everything together: percentage strongly agreeing pre and post TCAT service



Within the 4 projects with no comparative data, high percentages of service users (between 50% and 75%), gave the highest rating of 10 out of 10 to indicate that they <u>'strongly disagreed'</u> with the statement "I was passed from person to person without getting the support I needed".

Feedback on the statement "It helped me get other services and help to put everything together" was also reviewed. Between 38% and 42% gave the highest of level of agreement and most scored their agreement (out of 10) at 7 or above.

Developing referral routes to services and support

There is evidence not only of increased awareness among professionals who support people affected by cancer but of them using this knowledge to improve access to support. Another way in which TCAT has impacted positively on developing service integration and coordination is the success of many projects in developing new referral routes to services and support for people affected by cancer.

One example is a project establishing links with Breast Cancer Care to augment their TCAT work. This created a direct referral route for women to attend this charities' 'Moving Forward' course. Others have formalised links to local Macmillan Move More projects. Signposting too has been enhanced among TCAT Projects. For example, as a result of the NHS Lothian Phase 1 TCAT project, CNSs reported changes in their signposting practices. Previously dominated by Maggie's Centre's 'where now course' and the Macmillan Information Centre, patients now benefit from other local resources and non-cancer specific services such as befriending schemes. Other projects also report a similar widening access to services and support.

"at a local level we have already seen an uptake in services that were not well known" (wider stakeholder)

"I think there's huge untapped help we can be getting from community sources.and I think it's the trust that they're building up, like x never referred to y but they have now because they've met each other at events." (local project)

The role of local partners in actual project delivery

Over and above the development of referral and signposting links discussed above, inherent in all proposals was a need for 'others' to work with them to improve outcomes for people affected by cancer. Implementation success for most local TCAT projects was predicated on securing practical, operational contributions from local partner organisations.

Across TCAT the way in which local partners have been integrated into the delivery of the projects ranges from venue provision for assessments and events (such as within Dumfries and Galloway, Midlothian and North & South Lanarkshire) to new services

being created. For example, the phase 1 project hosted by NHS Ayrshire and Arran not only formalised referral routes into physical exercise programmes for people affected by cancer in their area, but also worked with local providers to develop a more targeted rehabilitation programme. Over 180 people with cancer have accessed the programme.

It is however only among the projects that implemented Health and Wellbeing Events that tangible <u>integrated service delivery</u> is most evident. These events were diverse in scale, scope and timing of provision, and all are exemplars of joint service delivery by a range of multi sector partners, direct to people affected by cancer.

Coordination of after care services and support

From the national evaluation perspective four local TCAT projects were found to have developed or enhanced the coordination of available aftercare services. These were the national project for teenagers and young adults, NHS Fife's lung project, NHS Lothian's Phase 2 project based at Wester Hailes and Fife Council's phase 2 project – Integrated Community Cancer Care project.

Although diverse in scope and coverage, these projects demonstrated and piloted a more identifiable 'whole systems' approach to providing after care services to people affected by cancer. Key to this was not direct service provision, but the promotion and implementation of coherent coordination of their after treatment pathway. Each project illustrated it was important for the new pathway to be visible and understandable to both contributing professionals and recipient patients and their carers. In addition, within each project there was a more identifiable 'entry point' into a service or pathway, which was not just a one-off intervention. More so than in other projects a clarity of objectives and remit among the agencies and individual professionals involved was also evident.

Conclusion

This Bulletin has used the national evaluation sources and analysis to answer the question:

To what extent has the programme enhanced service integration and coordination of after care services and support?

Overall the findings are positive. TCAT has acted as a catalyst for valuable local partnerships and the continued development of more integrated/coordinated service provision for people after treatment for cancer.

Whilst there is political, policy and practice value inherent in enhanced partnership, integration and coordination the real value of such work is for those affected by cancer.

The work of the national evaluation team during 2017 and 2018 will enhance the evidence. We are interviewing assessors and patients to understand better the ways in which integrated and coordinated support is delivered by professions, experienced by patients and contributes to improved outcomes.

Local TCAT projects have demonstrated that their various approaches to 'care after treatment' have improved awareness of and access to services and sources of support provided across the provider sectors. In particular projects that conceptualised this care as a 'pathway' and not a one-off intervention succeeded in improving the coordination of the available services and support.

TCAT is therefore a positive vehicle for progressing partnership working and integrated service delivery. As a result, the programme has significant potential to support solutions and contribute positively to the strategic and operational demands faced by health and social care services in Scotland.

The extensive groundwork and preliminary embedding of relationships, necessary for future joint practice has been carried out as a result of the programme. Attention post TCAT should focus on:

- Ensuring primary care is a key partner in the development of care after treatment
- Re-addressing the dominance of NHS representatives within the partnerships established via TCAT
- Determining and disseminating the future TCAT role of the Cancer Networks in furthering the integration agenda to support people affected by cancer
- Considering how local integration and service coordination can be enhanced and maintained, without the impetus of funding and focus provided by the national programme.

References

ⁱ Report on the Future Delivery of Public Services by the Commission chaired by Dr Campbell Christie. (29 June 2011)

ⁱⁱ <u>http://www.gov.scot/Topics/Health/Policy/2020-Vision</u> [accessed Feb 2016]

ⁱⁱⁱ Public Bodies (Joint Working) (Scotland) Act 2014 <u>http://www.legislation.gov.uk/asp/2014/9/pdfs/asp_20140009_en.pdf</u> [accessed Feb 2016]

^{iv} The Scottish Government. National Health and Wellbeing Outcomes: A framework for improving the planning and delivery of integrated health and social care services, 2015. ISBN: 978-1-78544-110-3. Available from: http://www.gov.scot/Resource/0047/00470219.pdf [accessed Feb 2016]

<u>https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/transforming-care-after-treatment-scotland.html</u> [accessed February 2018]

^{vi} Operational Guidance 11 July 2013

<u>https://www.alliance-scotland.org.uk/about-the-alliance/</u> [accessed March 2018]