TRANSFORMING CARE AFTER TREATMENT (TCAT) PROGRAMME

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Introduction

Macmillan National Programme Manager Gordon McLean on the objectives of the TCAT programme, and the next steps following its evaluation.

The Transforming Care After Treatment (TCAT) programme was a collaboration between Macmillan and NHS Scotland, delivered in partnership with the Scottish Government, regional cancer networks, health boards, local authorities and the voluntary sector.

A major component of the Scottish Cancer Taskforce workplan, TCAT’s overall aim was to help ensure that more people diagnosed with cancer are prepared for and supported to live with the consequences of cancer and its treatment.

This involved facilitating the development and implementation of models of care that:

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

The development of TCAT took place over a number of years. It built on evidence provided by people with cancer who were struggling with feelings of isolation, returning to normality, poverty, returning back to work, the consequences of treatment and concerns for carers.

We recognised a need to change how services across health, social care and the third sector are delivered. Services need to consider how care and support should be delivered after the initial management phase of treatment is complete, to support and enable people affected by cancer to be as healthy as they can and enjoy the best quality of life possible.

Health and social services and the voluntary sector need to work together with people affected by cancer to drive improvements to the services we provide.

There was also a need to move away from routine follow up, where one size fits all, to more individually-tailored aftercare arrangements. While some people affected by cancer still require consultant-led follow up, a growing proportion could be prepared and supported to self-manage. This would include remote monitoring, timely re-access to the system when needed, and support through information and advice on health and wellbeing, providing a longer-term impact.

Key principles for future practice were promoted as a result of the programme. These should be integral elements of all new models of cancer care after treatment. They include risk stratification, personalised care planning, information to meet individual needs, care coordination across care settings and rapid access to appropriate health or care professionals when problems arise.

TCAT wanted to promote a culture shift towards shared decision-making and supporting self-management.
The premise was that the wellbeing of people affected by cancer will be greater and their demand for services lower if they get support that is relevant to their needs.

Driven by the three cancer networks in Scotland, 25 test site projects were supported during the five years of the programme, led by health board leads or social care leads. Each project was developed with a number of pre-requisites, including:

- Service users were to be at the centre of informing the development.
- Each development was to test at least one element of Macmillan’s Recovery Package including HNA and care planning, treatment summaries, cancer care reviews, health and wellbeing events and risk stratification.
- A multi-partnership approach was to be developed to support a more integrated and coordinated approach.

The third and final phase of the programme focused on demonstrating that the learning from some projects could be transferred across a health board, a region or from one tumour type to another.

The programme has been successful in showing that the development of new and innovative approaches to supporting people affected by cancer after they have completed treatment. This has resulted in improved quality of support and efficiencies in service provision.

The programme has also helped to demonstrate a change in attitude and understanding of the importance of this area of the cancer pathway and the impact it has on the person with cancer and the wider family. It has also shown that it is essential to make this support available when a person is first diagnosed.

This issue of Sharing good practice looks at some of the innovations developed through the TCAT programme, and the ongoing work to evaluate the outcomes and spread the learning.

The Scottish Government committed to consider the learning from TCAT in its revised Cancer Plan produced in 2016. Steps are now being taken to make the principles developed through TCAT business as usual across health and social care for all people affected by cancer.

The individual project evaluations and the programme evaluations carried out by Edinburgh Napier University can be found at [www.macmillan.org.uk/tcat](http://www.macmillan.org.uk/tcat)

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Addressing the e-health gap to deliver person-centred care

An overview of digital innovations developed by TCAT projects, with the potential for both spread and scale.

Service users spend the bulk of their time in a community setting. With increased incidence and prevalence of cancer, and a health and social care system that is struggling to cope, greater use of digital solutions can help to improve the efficiency of this system. It can also enable us to be more responsive to the needs of service users at a time convenient to them.

The Transforming Care After Treatment (TCAT) Programme developed digital innovations that place people at the centre of their care and demonstrate improvements in clinical and experiential outcomes, making a real difference to people affected by cancer. In 2018 the Scottish Government presented its new Digital Health and Care Strategy, and many of the principles outlined have already been demonstrated by the digital solutions developed through TCAT.

TCAT funded two projects directly:

- the My Cancer Portal in NHS Highland, which is the largest geographic health board in Scotland,
- the ‘eCAN’ Lung Cancer follow-up project in NHS Lanarkshire.

There were also two further projects that were aligned with the TCAT project but not directly funded by it. These included creating a digital solution for the completion of treatment summaries in NHS Forth Valley and the development of a Scotland Service Directory by NHS 24 to allow service users to find local services to meet their needs.

NHS Highland’s My Cancer Portal is a digital platform that allows two-way communication between a person with cancer and their secondary care team. It is secure, linked to other local NHS digital systems and allows the service user to remain in contact with their clinical team without travelling long distances to see them in person.

The system provides access to holistic needs assessments, care plans, treatment summaries and quality assured information. It also allows service users to keep a digital note of any symptoms, which can be shared with the clinical team. Steps are now being taken to create a link to Scotland’s Service Directory, which will allow people to identify local services and address any wider psycho-social needs.

NHS Lanarkshire’s eCAN project used Docobo web software to provide a way for people with lung cancer to communicate their needs to clinical staff from their home. Patients were emailed a link to an online holistic needs assessment (HNA), which was quick and easy to complete. Clinicians received the patient’s answers and sent back pre-prepared written information to help address concerns. They could also signpost or refer to any relevant local services. Patients could request a follow-up through a 1:1 appointment or a telephone call, with 88% choosing a telephone call. This approach didn’t affect the therapeutic relationship or clinical outcomes between the nurse and the patient.
NHS Forth Valley’s ‘Tsum’ project was developed to enable cancer teams and people with cancer to work together to create a summary document detailing the type and stage of cancer, what treatment has been given and its intent, what side-effects are being experienced and how to manage these, and what late effects and ‘red flags’ to look out for going forward. It also includes who to contact if ‘red flags’ were identified, providing a route for rapid re-entry into the cancer team if needed, and a note of any other services involved or actions for the GP or patient.

This document is given to the patient and the GP, providing an easily accessible summary to support future decision making. Both patients and GPs have praised this system and the Scottish Government has called for every person diagnosed and treated with cancer to be provided with a treatment summary.

As a result of TCAT projects developing local service directories, and the challenge of maintaining them, Macmillan commissioned NHS 24 to develop and deliver Scotland’s Service Directory. This is an online directory of services delivered by health, social care and third sector providers in local communities. Sitting alongside NHS Inform’s online information, this development will help people to find information and access services available nearby. The directory can be used by people with cancer, carers, family members and health and social care staff.

All these examples illustrate how people in Scotland can access the information, tools and services they need online, to help maintain and improve their health and wellbeing. All were developed with patients and staff from the very beginning – helping to ensure confidence, buy-in and a product that is fit for purpose. These examples have been tested within cancer care, but the same platforms could potentially be used across a variety of other acute and long-term conditions, making spread and scale possible.

Further information

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Change through collaboration

Expanding the influence of TCAT projects through regional collaboration.

Scotland’s three regional cancer networks were central to the governance structure and day-to-day delivery of the Transforming Care After Treatment (TCAT) Programme. Through funding from the programme, each network appointed a clinical lead for TCAT.

It was the clinical lead’s job to support individual projects that were funded through TCAT, both practically and strategically. They were tasked with implementing a regional governance process, quarterly reporting, and using existing network structures to spread and sustain the outcomes from the projects. The aim was to ensure that the TCAT Programme would result in more than a series of successful pilots.

Of the 25 projects funded and delivered under TCAT, 11 were located within the West of Scotland. The West of Scotland Cancer Network (WoSCAN) regional lead for TCAT provided each of these 11 projects with practical support, expertise, guidance, and a forum for peer support and shared learning.

Through internal processes such as Managed Clinical Network (MCN) action planning and annual education events, WoSCAN ensured that the learning from each project was communicated to all clinical teams within the region. This methodology maximised the potential for an integrated approach and the regional roll-out of successful testing, while reducing unwanted variation in line with Scotland’s Chief Medical Officer’s vision for health and care.

This approach is demonstrated by WoSCAN’s Breast Cancer Follow-up Pathway, which was revised in 2017 under the significant influence of two TCAT projects: one in the North East Sector of NHS Greater Glasgow and Clyde, and the other in NHS Ayrshire and Arran.

Each of these projects began as quite different pieces of work. However, through shared learning, collaboration and regional working, both were able to demonstrate locally (and then regionally and nationally) how risk-stratified, person-centred care could be delivered efficiently and effectively. This means that people who have finished their ‘active’ treatment for breast cancer have a comprehensive final appointment with their clinical team, which incorporates a holistic needs assessment, care plan and treatment summary.

Where appropriate, the person is signposted or referred to local support to address psycho-social needs, for example the Macmillan Improving Cancer Journey team, Community Connectors or Breast Cancer Care’s Moving Forward Programme.

Those deemed suitable (approximately 70% of people on the breast cancer pathway) then enter the patient-led pathway. This means they are invited to attend a mammogram each year for five years, after which they enter the national breast screening programme (younger women continue to receive an annual mammogram until the age of 50). This new pathway reduces the number of clinical interactions with a medical consultant, yet personalisation and focusing on needs has resulted in people feeling they are better supported. Information, clarity around administrative processes and improved capacity through reducing unnecessary appointments also means that people with red-flag symptoms
know what to do, and rapid re-entry into
the system is guaranteed.

By influencing regional follow-up
guidance, these TCAT projects are now
positively impacting upon the care of
people treated for breast cancer within
at least four of Scotland’s 14 territorial
boards. These account for 49% of all
patients diagnosed with breast cancer
in Scotland each year.

Each of WoSCAN’s 13 MCNs are now
being encouraged to learn from this
approach and to embed risk-stratified and
person-centred care fully when revising
follow-up guidelines.

There are also examples of projects
that have progressed as a result of the
learning and relationships developed
under TCAT, but without dedicated
TCAT funding.

For example, WoSCAN’s Psychological
Therapies and Support Framework
has brought together cross-sector and
inter-professional experts to develop
and implement a framework to ensure
people affected by cancer have access to
psychological support as and when they
need it5. Positive outputs from this work
include improved partnership working
across the region, and improved access
to support and training for staff working
within the third sector.

Despite the TCAT programme drawing
to a close at the end of 2018, there is a
commitment from WoSCAN to continue
to spread and sustain the learning. This
is demonstrated not only through the
processes mentioned above, but by their
continuation of the regional clinical lead
role, which has recently been expanded
to cover ‘living with and beyond cancer’.

To find out more about WoSCAN, the
TCAT projects and the Psychological
Therapies and Support Framework go to
www.woscan.scot.nhs.uk

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Enabling culture change

Creating a better understanding of how holistic needs assessments can support professionals to identify and meet people’s needs.

NHS Tayside received funding for two projects through the TCAT programme. The first project was intended to implement key components of the recovery package – holistic needs assessments (HNA), treatment summaries and health and wellbeing events – within colorectal, prostate and head and neck cancer care. The second project was instrumental in setting up a service for people experiencing late effects of pelvic radiotherapy, using HNAs as the initial assessment with referral or signposting to appropriate existing services.

Historically, the cancer sites involved in the first project were already thought to be forward thinking, receptive to change and involved in several nurse-led initiatives, such as nurse-led cancer follow-up clinics. However, most of these developments focused on secondary care and still used a medical model of follow-up where one service was meant to fit all.

As specialist nurses, we often assumed that we could predict what people’s concerns were likely to be, as many of us had been nursing for decades and had specialist roles for more than 10 years. So initially, the introduction of HNAs was seen as another ‘tick box’ exercise.

However, the team agreed to test the change of practice by conducting HNAs at cancer follow-up clinics. One member of the team said. ‘At first, most of the patients were ticking the physical concerns, so I remained in my comfort zone. Physical concerns are my area of clinical expertise. But the main concerns were very different to what I had anticipated. I thought that the patient would want to hear the results of recent blood tests and CT scans and have any physical concerns addressed. In fact, they wanted to know about transport to the hospital as fatigue was an issue, as was attending appointments. Housing was another concern, as well as loneliness and isolation.

‘I was able to direct people to the Macmillan website for most things but did not know what was available locally apart from Maggie’s. I made it my mission to address the gaps in my knowledge by finding out what was available locally for people who had concerns that were not related to the physical aspects of the cancer.

I now appreciate that I do not need to know everything as long as I know who to refer or signpost to for additional support and help. Utilising HNA in practice has become business as usual for me.’

The main success is the fact that we have been able to sustain the work from the projects so that HNAs and care planning are an integral part of the patient journey.

This has not only been achieved within the three cancer sites that participated in the first project, but with other cancer patient groups such as those diagnosed with breast cancer, all oncology patients receiving chemotherapy and/or radiotherapy and upper GI cancers with others to follow.

This change in culture and practice would not have been achieved without a number of inter-related factors, which are all equally important: supportive leadership, true champions of the project and the development of a very proactive steering group, which has resulted in patients having an equal voice in shaping the way forward.
The TCAT project teams have been instrumental in supporting the initial work, but also assisting with the roll out to other teams. There has also been evidence of true partnership working with our local authority and other third sector colleagues so that there is mutual respect and an acknowledgement of a common goal.

Last but not least, support from all the Macmillan-funded services locally such as Move More, the libraries project and Improving Your Cancer Journey has resulted in a more cohesive approach to assessing and addressing individual patient needs.

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43 patients (51%) said afterwards they felt very confident to manage their condition.

61 patients (72%) said that their needs were completely met to confidently manage the consequences of their treatment.

49% of them (85) returned the questionnaire.
HNA and care planning in practice

Research Fellow Lucy Johnston and Macmillan Senior Learning and Development Manager Karen Campbell on the evaluation of HNA and care planning and the practice implications of the findings.

The national evaluation of the Transforming Care After Treatment (TCAT) Programme carried out by Edinburgh Napier University included an evaluation of the holistic needs assessment (HNA) and care planning.

The findings of this strand of the evaluation indicate that the provision and commissioning of patient-led HNAs and care planning cannot just be about what is done, but must prioritise how it is done by the assessor.

The use of a concerns checklist as an HNA tool assists the person affected by cancer to reflect on and identify their concerns holistically. This primarily held true for people who completed the list in advance of the assessment appointment. Once they have been ‘introduced’ into the assessment process, patient reporting and identification of holistic concerns can be ‘corrupted’ by the actions or processes of the assessor.

If an assessor’s role in the assessment process is not exclusively to conduct an HNA, for example if HNA is combined with surveillance or medical follow up, there is a risk that the desired holistic, recovery-focused assessment and process is not or cannot be fully implemented.

The professional discipline of the assessor was seen to impact on holism and the extent to which a truly person-led assessment was conducted. For example, we found that there may be a natural tendency for a nurse to prioritise immediate medical concerns. If the assessor prioritises or focuses on cancer-related issues, to the exclusion of reported wider, holistic concerns, then the patient’s agenda is not central to the assessment.

A truly patient-led, holistic assessment can be less likely to be realised earlier on in a patient’s cancer journey (during treatment or immediately post-treatment). At this time, functional or medical issues may rightly be at the forefront of both the patients’ and the assessors’ minds.

Analysis of concerns data revealed that HNAs carried out closer to diagnosis or end of treatment, and/or by a cancer nurse specialist, are associated with higher reporting of physical or medical-related concerns such as hot flushes, dry mouth, diarrhoea and constipation.

Care planning

An effective care plan fulfils two critical functions. Firstly, to support self-management activity through the co-production and ownership of the plan by the person with cancer. Secondly, a care plan must support individual action and solutions and not be just a record of a discussion.

However, patient interviews showed limited evidence of either of these functions. People had vague, if any, memory of an actual ‘plan’ and none could provide examples of how they had used the document following their assessment.
The review of care plans found that most plans were dominated by the recording of the fact that downstream care agencies had been suggested. Assessors have a key role in directing people affected by cancer to appropriate, local sources of support. However, it was unclear how the HNA and care planning process maximised actual uptake of appropriate support services.

In achieving the aims of HNA and care planning, the uptake and utilisation of services and support outside of the NHS, post-assessment, is the crucial mediating mechanism. The findings indicate that the energy currently being put into identifying concerns through the HNA is not matched by that required to actually resolve or alleviate them (care planning and care plan).

We found that the role of the assessor and the assessor’s response to the identified concerns can have an impact on the extent to which the assessment is both patient-led and ‘holistic’. As a result of this evaluation we recommend that:

- HNA and care planning must be offered to all people with cancer from the point of diagnosis, as part of a co-ordinated intervention throughout their cancer experience.
- All HNA and care planning consultations must focus on recovery.
- The role of the assessors will develop to act as consistent point of conduct between treatment centres, primary care and community assets, This will provide reassurance, reinforcement and maximisation of uptake of community resources to enhance self-management.
- The utility of care planning and plans must be further evaluated and enhanced.
- A longitudinal evaluation of the utility and effectiveness of care planning and care plans for cancer survivors and their role in increasing uptake of support in the community is undertaken.
- Piloting of different approaches is undertaken, including technology-based interventions to increase the level of reinforcement and reassurance provided to people with cancer by HNA and care planning services.
- A needs assessment of required training and mentoring to support optimal implementation of HNA and care planning takes place.

Further information

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An underpinning principle of the Transforming Care After Treatment (TCAT) Programme was to include patients and carers in decision-making at all levels. At the local, regional and national level, the programme wanted to ensure that the opinions and experiences of patients and carers truly influenced and informed the development, implementation and final evaluation of individual projects and the wider programme.

Perceptions of co-productive approaches, and commitment to them, varied widely across staff who worked on the TCAT Programme. Making sure that all staff had access to support in developing their user involvement plans at project level, and showing how the user voice would be incorporated into the development of local projects, were key factors in the success of project applications.

Strategically, a national group called the Cancer Experience Panel (CEP), consisting of patients and carers with recent experience of cancer, pioneered a consultative role within the programme. This was an integral part of steering its progress.

The group was responsible for holding the TCAT Board to account for how the programme developed and how resources were allocated. There was an equal sharing of responsibility between the group and TCAT professionals for funding decisions on project bids submitted to TCAT was an early indicator of serious intent on the part of both the CEP and the Board to make sure that the principles of partnership working became embedded in the programme.

User involvement was not consistent across all areas of the programme. There were several issues that influenced the level of user involvement, including:

- varying views among practitioners and managers about what user involvement means,
- varying experiences of working in partnership with service users,
- the need to compartmentalise user involvement
- lack of knowledge of the strategic policy drivers towards a co-productive approach.

However, across projects there was a willingness to learn how to progress a different approach to user involvement, which was more meaningful and impactful.

### Emerging strategies

The TCAT projects operated in a wide range of contexts and no single model or structure of user involvement could be applied across all projects. The following are some of the learning points and emerging strategies for user involvement:

- Work with staff to increase their expectations and intention around user involvement. This is key to developing successful partnership working.
- Provide very specific support to staff and assist them to interpret user involvement as it applies in the context of their own projects.
- Seek examples where users have influenced development and direction in their projects. This is an effective way to sharpen the focus of project staff on the influencing elements of user involvement.
- Many people with experience of cancer need support to perform an effective role on decision-making groups.
Specific training was developed to give TCAT volunteers a clear understanding of the role and its importance to project development.

During the first half of 2018, the CEP reflected on the key learning points from four years of involvement with TCAT.

The key messages, as described by members of the CEP, are:

**Partnership and cooperation**
- More cooperation, sharing of knowledge and a greater focus on partnership working is needed from agencies working in the field of user voice to improve outcomes across the sector.
- People with lived experience can work across boundaries and lead the way in breaking down organisational barriers. User representatives need to push hard when necessary to encourage a greater focus on partnership working from professionals.
- Training and capacity-building can help shift more professionals towards a partnership approach and help user representatives to realise their potential as catalysts for change.

**More than a job**
- Practise non-professionalism. Involvement groups are not just another professional meeting. People invest their time and energy in them because they want to, not because they need to.
- Peer support happened around the edges of TCAT groups, while meetings themselves remained business-like and agenda-driven. Creating a balance that allows members to access informal support while remaining focused on the aims of the group can create successful involvement groups.

**Strong leadership**
- Committed and consistent leadership and drive creates the right environment for effective user involvement.
- Clear goals and a plan of action from the outset is important, especially when timescales are tight, to ensure strong engagement.
- Groups must be connected to decision-making and decision-makers. Progress made should be visible and timely, so that people feel they are making a difference and remain engaged.

**Great communication**
- Making groups accessible, both physically and emotionally, through sensitive communication, breaks down the barriers that inhibit people from attending groups.
- Listen well. People need to feel they are being heard and resulting actions must be visible.
• Smaller groups can be more effective than larger ones. People can relax and express their views and experiences more readily.
• Keep written communication friendly and jargon-free.

Sustaining the message
• Although the experience built up by users involved in groups should be seen as a valuable resource, it should not inhibit professionals’ ideas of how a group is set up or progresses.
• Mapping out the ‘life’ of a group helps members understand its purpose and future milestones.
• A group that has worked successfully together for a year or two is a valuable resource with a strong contribution to make.

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Resources

TCAT programme evaluations
For more information about the TCAT programme, including individual TCAT project evaluations and the wider programme evaluations carried out by Edinburgh Napier University, visit www.macmillan.org.uk/tcat

References


Have you got an idea for a future issue of Sharing good practice? Get in touch at macvoice@macmillan.org.uk