

SERVICE REDESIGN

Using patient experience to improve outcomes after treatment

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Abstract

The Transforming Care After Treatment (TCAT) programme aims to improve care for people living with and beyond cancer in Scotland. The direct involvement of people affected by cancer is integral to the programme's design and its overall success. Under the TCAT programme a project team in NHS Ayrshire and Arran has worked with people affected by cancer to review and redesign its breast and colorectal cancer pathways. The outcomes of the project have demonstrated the value of ongoing user involvement in the development of an intervention. This allows for rapid feedback and insight into experiences, and services have become more efficient, effective and person-centred.

Keywords

cancer, living with and beyond cancer, patient experience, service redesign, transforming care after treatment

IN 2000, Our National Health stated that a patient focus should be embedded in the culture of the NHS in Scotland (Scottish Executive 2000). To make this happen, listening, understanding and acting on the views of local communities, patients and carers was to be given the same priority as clinical standards and financial performance (Scottish Executive 2000).

A framework to support change and delivery of services, and to build on existing work done in health boards, followed in 2001 (Scottish Executive 2001). The aim was to give patients and carers greater involvement in service design, change and delivery.

Evidence suggests that by placing people and their direct needs at the centre of health and social care service design, services are more likely to achieve and sustain quality, even under growing internal and external pressures (Department of Health 2012). Patient and public involvement has also been shown to result in (Coulter and Ellins 2006):

- » Increased patient satisfaction.
- » Improved confidence in being able to self-manage conditions.
- » Improved compliance with treatment plans.
- » Increased participation in monitoring and prevention schemes.

This strategic focus in Scotland has continued in cancer services and is considered here in relation to the Transforming Care After Treatment (TCAT) programme (Scottish Government 2008, 2016a).

Transforming Care After Treatment

The TCAT programme is a partnership between the Scottish Government, Macmillan Cancer Support, NHS Scotland and local authorities, which supports redesign of care after active treatment for cancer. The five-year programme was launched in 2013 and aims to support and enable people living with and beyond cancer to live as healthy a life as possible for as long as possible (Scottish Government 2016b).

Earlier detection of cancer, better treatment outcomes and an ageing population mean that more people are being diagnosed with, and surviving, cancer. However, research shows that despite living longer, people are not necessarily living well (Macmillan Cancer Support 2014). Many people experience ongoing and late effects of cancer and its treatment, and this can have a profound effect on their quality of life (Langendijk et al 2008, Macmillan Cancer Support 2013, DeSantis et al 2014). As a result, cancer care needs to be transformed to ensure people's physical, emotional and financial needs are met.

To support the change in cancer service delivery, a call for funding was issued before the official launch of TCAT. Teams were invited to submit proposals that would demonstrate a move towards person-centred, high-quality care which reduced unnecessary follow-up and better supported people affected by cancer. In light of this call for funding,

NHS Ayrshire and Arran worked with local partners and patients and carers affected by breast cancer, to put forward an application which would support a change in breast and colorectal cancer service delivery. This proposal and nine others were accepted during the initial phase of TCAT funding.

TCAT structure

From inception, the TCAT programme board was a strong advocate for the involvement of people affected by cancer. Before a second call for funding was issued, a TCAT service-user involvement manager was employed and a service-user group was established; this group has recently been renamed the cancer experience panel (CEP). The service-user involvement manager and the CEP chair hold a seat on the TCAT programme board (Figure 1). Thus, the CEP could influence decision making at a senior level and was given an equal say in which bids should be funded during the second phase of TCAT. After this second funding phase, 15 additional projects were funded, one of which is led by North Ayrshire Council and links with the NHS Ayrshire and Arran phase 1 project.

Each project, whether funded during phase 1 or phase 2, reports to the local cancer network – West of Scotland, North of Scotland, or South East Scotland – and each network holds a seat on the TCAT programme board. This structure aims to ensure the learning outcomes of each project are shared and that the projects can be spread with maximum effect.

After receipt of funding the NHS Ayrshire and Arran Macmillan TCAT project lead established a dedicated patient and carer panel to ensure meaningful involvement of people affected by cancer. When a second Ayrshire project was funded, the TCAT patient and carer panel, and the two project leads agreed to work together in support of the projects.

The TCAT patient and carer panel comprises individuals who have had a recent breast or colorectal cancer experience, either as a patient or carer. They are involved in decision making and service development, ensuring the project is fit for purpose. A role/task description was developed to clarify the role of TCAT patient and carer panel members, and training was organised to equip members for this role and improve the effectiveness of their contribution to TCAT projects. Training was coordinated by the TCAT service-user involvement manager and a clinical psychologist and included sessions that focused on:

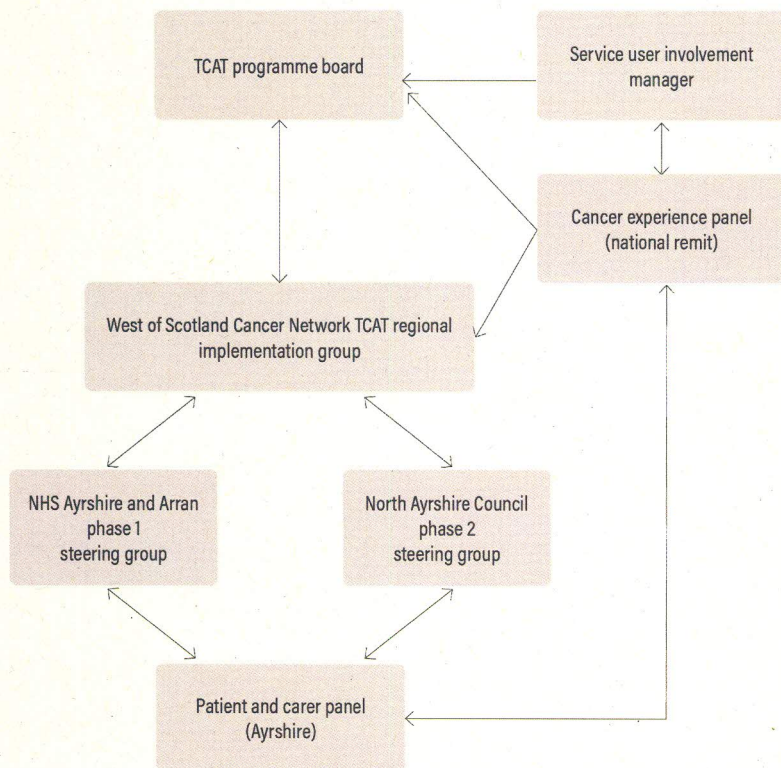
- » The unique role and contribution to TCAT.
- » Communicating effectively in meetings.
- » Managing challenging scenarios through role play.

Responses to an anonymous questionnaire distributed to members at the end of the training session found the training was well-structured and essential in promoting active involvement by the local TCAT patient and carer panel members. These findings were verified through local feedback given by attendees to the panel's chair.

Patient and carer panel roles and responsibilities

Lessons learned from previous patient engagement work included the importance of sharing roles and responsibilities. This helps to ensure everyone has a voice and there is equity among the group; it also helps to minimise the effect on any one individual and the time they can offer to the group. These lessons were applied when organising the TCAT patient and carer panel and, as a result, one panel member agreed to take on the role of meetings organiser, two panel members agreed to represent the panel on the phase 1 steering group and two other members agreed to represent the panel on the

Figure 1. Abbreviated Transforming Care After Treatment reporting structure



phase 2 steering group. By having two panel members on each steering group the members felt better supported and more confident to participate in the ensuing discussions. 'Stand-in' representatives were identified from the panel for the rare occasions when one of the nominated representatives could not attend.

Effect of membership on individuals and the project

Patient and carer panel members were always encouraged and, through training and honest dialogue, empowered to speak openly about their effect on local work, the impact of involvement on their lives and the effectiveness of the group. As a result, one member said to the TCAT project lead:

'I believe from the small amount of time I've been with the group that you do give the representatives a great deal of input with all aspects of the work. I also like the fact that you deftly manage those in the group who wish to express their personal experiences and to distil their highly emotional views into objective and salient points. My recommendation would be to continue as you are and maintain your flexible response to change' (panel member 1).

Another recorded a short video in which they said: 'It's great that people are living longer after a cancer diagnosis; and I am one of them. But it does bring its challenges and this is where I feel TCAT comes in to play... the project manager, and her team are so enthusiastic and committed to addressing these areas of concern and I felt it a real privilege to work alongside them. I've loved being on the panel, meeting a variety of people and I hope in some way I've contributed something back in to the community. I've always felt heard and included in discussion and decision-making. Communication has been excellent. My hope is that everything that TCAT has achieved can become sustainable practice' (panel member 2).

Ayrshire and Arran's TCAT project and panel input

Under the TCAT programme, NHS Ayrshire and Arran has introduced initiatives to support holistic care throughout the extended cancer pathway. One initiative was the introduction of community health and well-being clinics (HWBCs). The clinics are aimed at people with a diagnosis of breast or colorectal cancer and individuals are routinely invited to attend between six and eight weeks after the end of their active treatment, that is, surgery, chemotherapy or radiotherapy. Held in community NHS venues throughout the locality, the clinics also aim to deliver care

closer to home and support a shift away from acute hospital care. During an appointment, which is led by a Macmillan health and well-being practitioner, we aim to identify and meet the needs of individuals. This is done through use of an electronic holistic needs assessment (HNA) – the cancer concerns checklist – and care planning process which has been shown to be effective in previous evaluations (Young et al 2012).

Despite the community HWBCs being embedded as a routine part of care, ongoing monitoring and evaluation of the clinics showed that uptake and attendance were lower than expected. Only 57% of invitees attended and 20% of people failed to attend without notification. In response, the patient and carer panel members suggested changes to the information provided to patients before the clinics and the administration processes undertaken. They recommended:

- » Developing an information leaflet about the clinics to be given to patients by their clinical nurse specialist at their final oncology appointment. This would show continuity of care and potentially encourage attendance through advocacy of the clinic by clinical teams.
- » The pre-clinic invitation letter sent to patients after cessation of their treatment should be edited to better explain the purpose of the clinics and what happens during an appointment.
- » The introduction of a reminder phone call one week before each appointment. This would ensure that people managing multiple appointments and those with memory problems did not forget their appointment.

The effect of implementing the changes suggested by the TCAT patient and carer panel was significant with:

- » Overall HWBC attendance increasing by 3%.
- » Non-attendance without cancellation rates decreasing from 20% to 10%.
- » User cancellation rates increasing from 24% to 31%.

Reduction in non-attendance and an increase in the number of people providing advanced notification of appointment cancellation allowed staff to be more efficient. This also increased the availability of appointments.

Wider effect of TCAT patient and carer panel

TCAT patient and carer panel members have also been involved in regional and national TCAT learn and share events, as presenters and as delegates. One of these events resulted in the instigation of a regional

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review of services available to children who had a relative with cancer. The review led to the development of a local (completed) and regional (under development) service directory, which is designed to support care provision and signposting by health and social care professionals to available services.

Project evaluation

To provide a greater understanding of the effect of this project and evidence for future planners and commissioners of comparable services, an evaluation plan was developed during the project planning stage. While some qualitative data were collected by the local TCAT team, an independent evaluation was provided by NHS Ayrshire and Arran's public health department and further data analysis was undertaken by Edinburgh Napier University who are providing an external evaluation for the wider TCAT programme.

The work by NHS Ayrshire and Arran's public health department included establishing a baseline against which the new pathways could be measured. A questionnaire was sent to all patients diagnosed with breast cancer in 2013/14, all patients diagnosed with colorectal cancer in 2014/15 and, approximately three months after their appointment, all those invited to attend the HWBCs. Eleven semi-structured interviews were also undertaken to elicit more detailed information about the new model of service delivery from users. The TCAT patient and carer panel reviewed all evaluation documentation and questionnaires and interview schedules were tested resulting in amendment and finalisation.

Evaluation of patient experience has focused on:

- » HNA across the care pathway.
- » Experience before changes in the care pathway.
- » Non-attendance at HWBCs.
- » The new care pathway.

Evaluation findings revealed that breast cancer patients following the TCAT care pathway report:

- » A reduced number of physical concerns (56% new vs 64% old), practical issues (20% new vs 29% old) and concerns about cancer recurrence (37% new vs 70% old) than those on the previous pathway.
- » More satisfaction in terms of the support received from hospital staff at the end of treatment compared with those on the previous pathway (56% vs 48%).
- » Most patients on the new pathway also found the electronic HNA and HWBCs helpful (72% and 89% respectively). These findings suggest that the changes introduced locally by the TCAT project have helped to identify and address the needs of people diagnosed with cancer, thereby better supporting them after treatment.

Information received via a self-completed postal questionnaire sent to those who did not attend the HWBC, approximately 40% of patients invited, found that 66% did not think they required any further support because they either had no concerns or were well supported. However, some of those not attending may need additional input and future work is required to understand how to address their needs.

The results outlined here have been considered locally and will be presented to the West of Scotland TCAT implementation steering group and the TCAT programme board. As a result the project has the opportunity to influence services delivered across Scotland.

Conclusion

The skills and experiences of the TCAT patient and carer panel during the development of new models of cancer follow-up have helped this project respond to the needs of people affected by cancer. User involvement has also enabled this service to become as effective as possible through articulating service aims to patients and promoting better attendance at HWBCs. Attendance at HWBCs has been shown to be helpful to patients, and it appears that the integration of HNA and care planning into routine treatment pathways is feasible.

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