

Transforming Care After Treatment: Evidence and Learning Bulletin

User Involvement and TCAT

**Co-produced by the Cancer Experience Panel &
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 TCAT. This work includes a rolling programme of Evidence and Learning Bulletins on specific topics.

This is the second of a planned series:

2017:

- Holistic Needs Assessment: Implications for Practice
- TCAT and the Patient Voice: From Involvement to Influence
- Measuring Outcomes in TCAT: A Briefing Paper

2018:

- Community Based Projects: Evidence and Learning
- Mechanisms of HNA and Care Planning – A Realistic Evaluation
- Two special interest/themed bulletins
- Final 'wrap up' report on the national evaluation

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

Purpose of the Bulletin

This Bulletin presents the learning to date from a national evaluative perspective on the extent to which, as a result of the Transforming Care After Treatment Programme (TCAT), there has been increased service user involvement and the patient voice. An additional purpose is, in collaboration with the TCAT Cancer Experience Panel, to present their proposed model of user involvement and essential components for maximising user influence.

Sources

Since summer, 2014 a number of evaluation methods have been deployed within a work strand dedicated to the evaluation of the patient voice. In particular, longitudinal data over three years tracks the extent to which wider stakeholders¹ consider overall that the patient voice is part of TCAT.

These are presented in detail in the Baseline and Interim reports and accompanying Technical Appendix (on request from TCAT@napier.ac.uk). Further activities in collaboration with the CEP included:

- November 2016: Presence at CEP Conference. Interactive stand allowed participants to contribute definitions and ideas to assist in the initial specification of the components of user influence. Participants viewed the continuum model of user involvement and placed themselves on it
- October/June 2017: Co – production with the CEP to define the components of a TCAT User Influence Model
- Findings from an online survey of local TCAT project patient/carer/service user representatives (October 2017). This was sent to 106 local representatives of 18 local projects and achieved a response rate of 36% (n=38).

Background /context

Involving people and the public in the design, delivery and assessment of health and social care services is not a new conceptⁱ. With roots in citizenship and community activism and participation, the role of patients and service users has increasingly become mainstream and a main stay of local and national policies.

“A service designed for and involving users” was the aim of the Scottish Government in 2001.ⁱⁱ For cancer services specifically, the ambition of the Scottish Cancer Plan (2016) is that every individual should be involved in decisions about their own care and treatment and that work should be also aimed at strengthening ‘the collective voice’ of patients, service users and those close to them.

¹ An online survey of wider TCAT stakeholders was distributed in November 2015, 2016 and 2017. These wider stakeholders included members of national and regional TCAT structures and those involved in local project implementation steering groups

There are numerous conceptual and theoretical models of involvement^{iii,iv,v,vi} each with their own proponents and detractors^{vii} and a range of published standards and guidelines and good practice guides.^{viii,ix,x, xi}

The Cancer Reform Strategy, Patient Experience Working Group (2007)^{xii} concluded that a key way to improve patients' experiences of cancer care was to "involve service users in decisions about reconfiguration and service development".

TCAT's ambitions for user involvement and the patient voice

Ensuring a relevant and influential role for people affected by cancer at all levels of TCAT (nationally, regionally and locally) is one of the programme's main aims. The Programme has the following outcomes^{xiii} for user involvement and the patient voice:

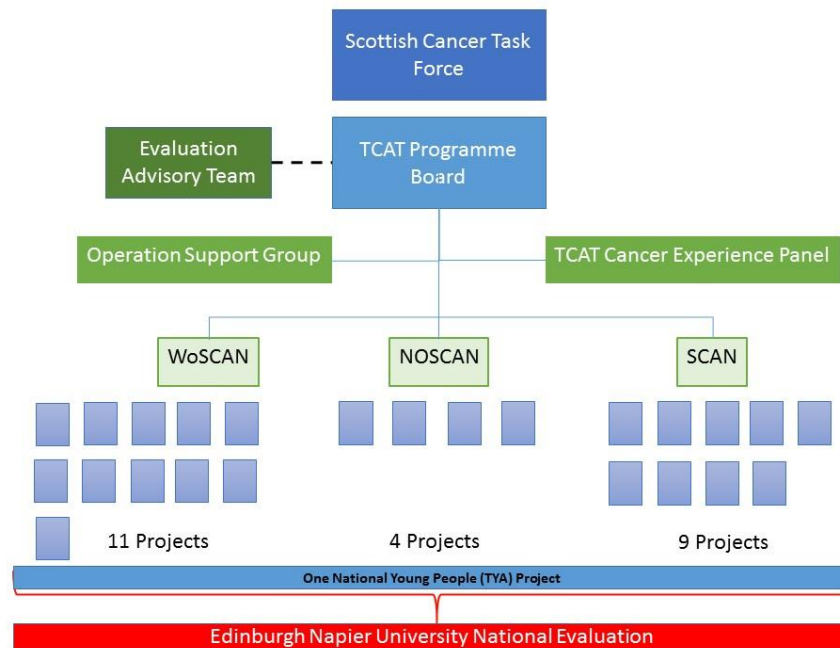
- There is greater involvement in planning of after care by patients and carers
- People affected by cancer are more involved in shaping cancer services
- Collaborative activity is or can become embedded.

The programme prioritised the role of the 'patient voice' by building it into TCAT's structure and implementation processes. (See Figure 1).

Remits

In the terms of reference for the TCAT Programme Board, there is a responsibility to ensure the views of patients and their families are at the core of planning and delivery of the programme. Part of the role of each regional TCAT Implementation Group, within Scotland's three Cancer Networks (NOSCAN, SCAN and WoSCAN), is "supporting the inclusion of the patient voice within the TCAT programme".^{xiv}

Figure 1: Structure of TCAT



Cancer Experience Panel (CEP)

Nationally, the TCAT programme set up a Cancer Experience Panel (CEP) whose members all have lived experience of cancer, as either a patient or informal carer. The role of the CEP is to innovate and strengthen the approaches used to involve patients, carers and the public in the development of the TCAT Programme. ^{xv}.

An important function of the CEP has been to build a shared understanding and strong sense of aspiration around the aims of the involvement work across the programme.

The CEP contributed to the assessment process for bids for Phase 2 of TCAT. The CEP score had a 50% weighting in the overall process and for many stakeholders this signalled loudly the importance of user influence within the programme.

Dedicated Officer

A TCAT Service User Involvement Manager, based at THE ALLIANCE², supports the CEP. This role involves recruitment, facilitation and building resilience within the group as well as relationship building with other projects and agencies on the group’s behalf. Another key area of responsibility is developing meaningful user involvement within the TCAT projects. For the post holder this involved supporting the projects to put in

² <http://www.alliance-scotland.org.uk> [accessed Nov 2017]

place structures and mechanisms to ensure people with experience of cancer were involved in all aspects of project delivery and development.

Programme criteria

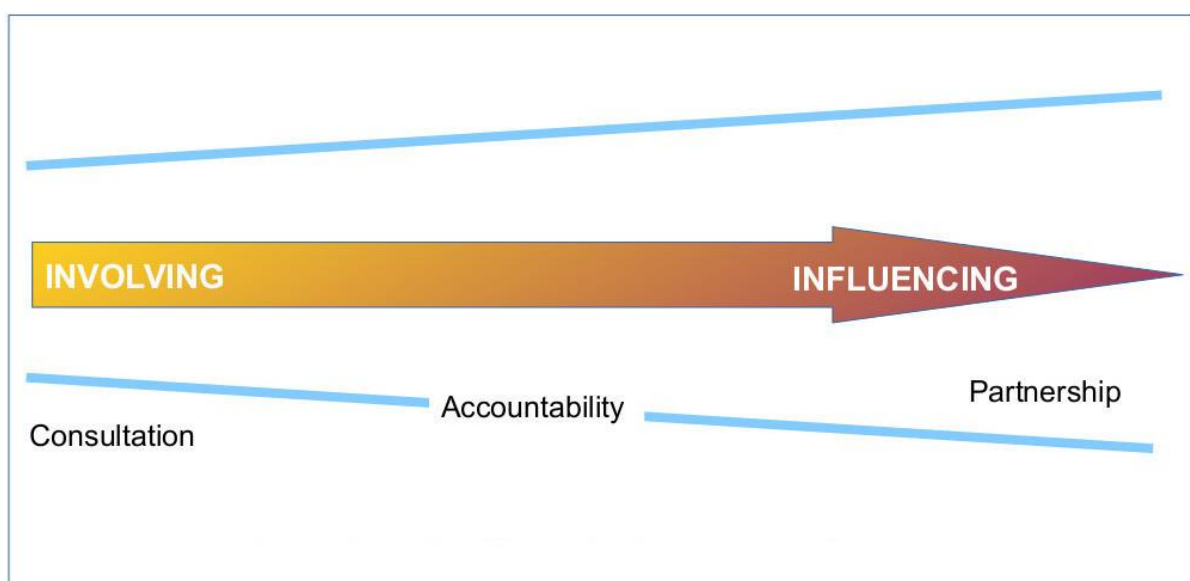
TCAT has been 'operationalised' via the commissioning and funding of 25 local projects, tasked with the development, testing and evaluation of new models of after care service delivery and practice. The criteria for programme funding of projects included the provision of evidence of "active and meaningful patient and public involvement within any proposed development project".^{xvi}

Continuum model of user involvement

The impact and outcomes of user involvement have been reviewed ^{xvii,xviii, xix,xx} in health and social care in general and in cancer services specifically.^{xxi, xxii} All highlight the need to understand the 'model' of involvement being evaluated and the challenge of evaluating user involvement for which there are no 'set' or universal measurement indicators.

The CEP conceptualised the patient voice as a continuum of involvement. (See Figure 2). The use of a continuum ensures that within TCAT all and any sort of involvement users engage in is valued.

Figure 2: TCAT User Involvement Continuum



This continuum model was used to further frame the CEP’s collaboration with the national evaluation team. Meetings and discussions initially focussed on the question “what does successful user involvement look like/feel like? And latterly upon the question “how can we measure progress and success within the TCAT programme?” In answering these questions, relevant literature^{xxiii,xxiv, xxv,xxvi,xxvii, xxviii} was reviewed and the experiences and motivations of the CEP members shared. This process resulted in the co-production and identification of four key components of successful user influence. These are:

- Inclusive
- Supportive
- Positive & Meaningful
- Embedded

The meaning and content of each component was further detailed at a collaborative meeting and is shown in Table 1.

Table 1: Components of a model of user influence

Component	Description of component i.e. what would an effective model of user influence look like/feel like?
Inclusive	<ul style="list-style-type: none"> • Wide representation: Range of ages, genders etc and experiences of being affected by cancer are represented (not just patients at end of treatment) and not just one individual being seen as ‘representative’ • Users are aware of routes into involvement and the opportunities to be involved are widely publicised • Equitable: the challenges to involvement posed by location/distances and possible ill health are addressed (e.g. use of face to face technology) • Range of different ways to be involved are available (which also address time available, possible poor health) • Retention of those involved is high and/or explainable/understood if not
Supportive	<ul style="list-style-type: none"> • Those involved report feeling supported in their role- • Training provided to staff and users • Provision of professional support/infrastructure • Those involved report feeling respected • Those involved feel ‘well informed’ to contribute meaningfully
Positive and meaningful	<ul style="list-style-type: none"> • Those involved report experience as enjoyable • Those involved consider they ‘get ‘something back’ from the experience • Evidence of user influence recorded and monitored • Feel their involvement has made a difference
Embedded	<ul style="list-style-type: none"> • Recognised, separate identity and role for users (for example user involvement is a criteria for project funding) • Agreed remit of patients/carers including time commitments • Communication channels to decision makers are clear and formal links to relevant agencies /organisations are established • Voice is heard (not just a presence) • Involved users report they have been listened to • Part of a bigger picture of service change (local and national)

Using the evaluation sources available some aspects of the four components of the continuum model are discussed in more detail below.

Inclusive

How have users been involved in TCAT?

The CEP Chair and Vice Chair attend Programme Board meetings and there is CEP representation at each of the three regions TCAT Implementation Groups. These are held quarterly.

All local projects are able to evidence some form of user involvement. The picture across TCAT is however mixed in relation to approaches, activities, level, frequency and duration of involvement.

From the user representative survey, it was found that all users involved in TCAT reported attending meetings (see Table 2). For some projects, a single user attended the formal operational or strategic TCAT group whilst other projects set up dedicated 'user involvement' groups, which ran parallel to the steering group.

This predominance of monthly or bi-monthly meetings as a mechanism for involving users is reflected in the average time users reported spending being involved in TCAT. Almost two-thirds of representatives reported (65% (22/34)) spending three hours or less per month and of these 41% spent two or less hours per month (9/22).

Members of the CEP typically reported higher levels of involvement - with some reporting spending over 3 days per month on TCAT related activities. The most common activities users have been involved in is shown in Table 2. The main vehicle for user involvement within TCAT, is the round table meeting format and many of the meetings are large.

Table 2: Top 4 activities of users involved in TCAT

Activities/types of involvement	n	%
Attending meeting	34	100
Preparing for meetings in advance	17	50
Presenting at workshops/conferences	12	35
Preparing resources (invites/leaflets)	8	24

(n=34)

However, the way user representatives describe their involvement belies the generic top 4 activities. It illustrates the continuum of involvement through to influence. It ranged from very general descriptions of how they had contributed - for example by saying they “*helped shape the project*” to the detailing of specific contributions such as advising on appropriate referral routes and medium of invitations to the project to better suit user needs and preferences. Consultation and development on project resources constituted a key role for user representatives. Especially as seen below in the second quote ‘*de jargonising*’ was a key activity.

“I was involved in a sub group that had input to the development of resources, both print and video”

“I have influenced the format and content of the documentation and ensured no jargon is used”

One in three user representatives had presented at local workshops, wellbeing events and/or national conferences. Both users and project staff regard this as very worthwhile activity and the perceived value of people with lived experience of cancer raising awareness of local services and sharing their story with practitioners was evident in all sources.

“we went to see a medical group of nurses and I explained that as they are in direct contact with cancer patients they could refer them to TCAT for support”

Within TCAT users were also involved in two other activities:

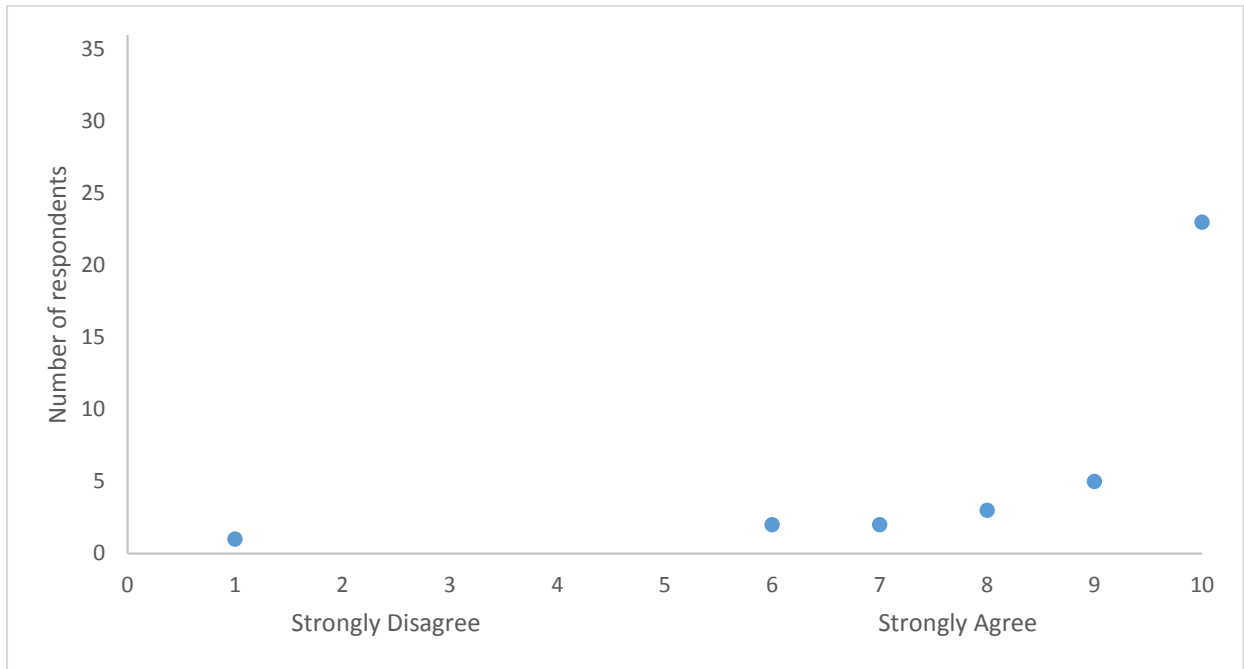
Informing the design of the proposed project: through collation of anecdotal feedback (8 projects), the use of previous survey/feedback activity to inform their proposed service delivery priorities (10 projects). Prior to submission, four projects had gathered user/patient feedback on their specific TCAT project proposals.

Evaluation contribution through feedback: by taking part in interviews, group discussions or returning surveys/questionnaires.

Supportive

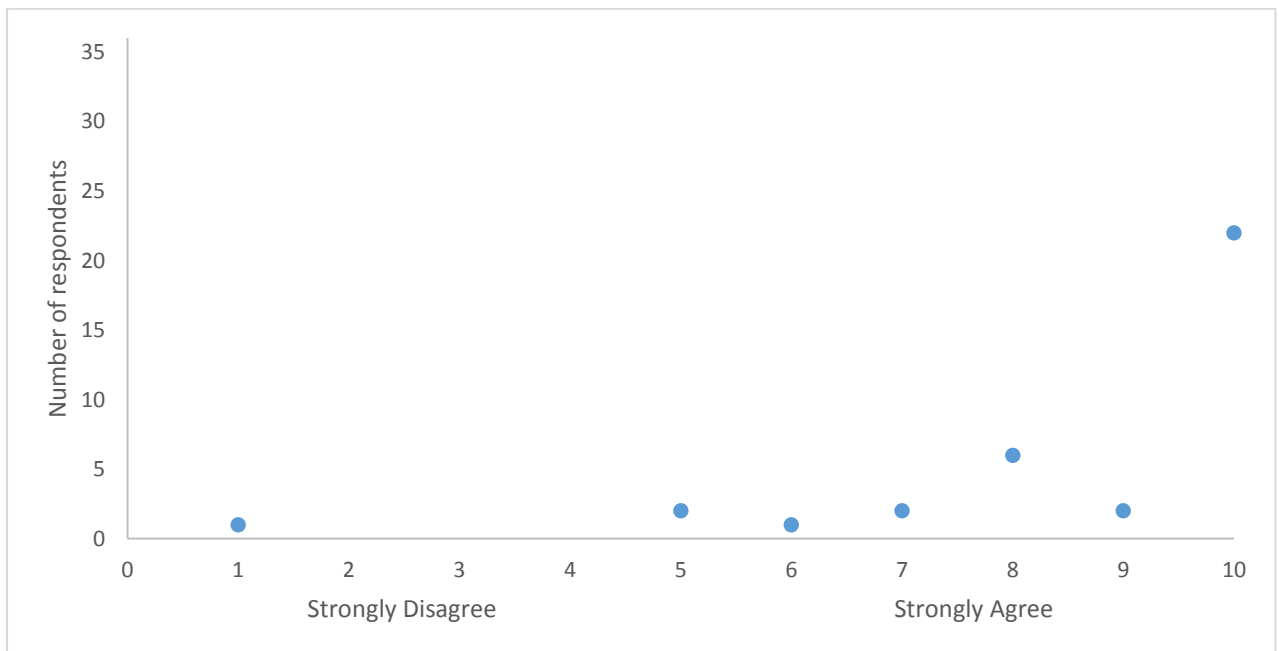
When asked the extent to which they agreed with the statement “I am respected”, user representatives provided a range of answers. The majority (n=23) ‘strongly agreed’ with the statement, yet significant numbers rated the respect they felt as lower than 10 out of 10.

Figure 3: User representative agreement with the statement: I am respected



The majority of local user representatives strongly agreed with the statements “I am supported in my role”. Shown in Figure 4.

Figure 4: User representatives agreement with the statement - I am supported in my role”.



The high numbers of users involved in TCAT reporting that they felt supported and respected is positive and encouraging. The national evaluation work strands identified two aspects that may have contributed to this. These are:

- Availability of dedicated professional support
- Provision of Training

Both involved users and staff of the local projects singled out the valuable role of the TCAT User Involvement Manager. It was felt the existence of an officer in a dedicated role provided continuity to users, motivation, and prioritisation to local projects in addition to practical input in areas such as administrative issues and timescales.

The TCAT Service User Involvement Manager“has been more than enthusiastic in his support to us to really make sure we have incorporated the patient’s voice into our project”

The TCAT Service User Involvement Manager“has been most persistent in reminding our projects as to the importance of meaningful patient involvement”

Other studies of user involvement have also found this role to be critical to successful user involvement.^{xxix} In addition, the need for training of both users and service practitioners has been highlighted as a prerequisite for success.^{xxx, xxxi}

The need for training for local TCAT representatives and CEP members was identified by the TCAT User Involvement Manager. He became aware of increasing numbers of patients and carers becoming involved in the TCAT projects' design and delivery processes with little experience of participating constructively in meetings with health and social care professionals.

In order to support people in this situation, practical tools and strategies for influencing meetings within this culture were required, along with an understanding of the expectations and aspirations for user involvement in the context of national, governmental policy.

This training aimed to build the capacity of those involved and to increase their understanding, knowledge and aspirations for involvement in the future. (See Box 1)

Participants were either members of the Cancer Experience Panel or patient/carer representatives from the TCAT projects. Lesley Howells, Consultant Psychologist for Maggie's and Centre Head for Maggie's Dundee designed and delivered the training with assistance from the TCAT User Involvement Manager.

Box 1: Intended Outcomes of TCAT Patient and Carer Involvement Training

- Participants gain confidence in performing their roles in TCAT groups
- Participants are equipped to overcome negative, or unconsciously obstructive attitudes, responses and situations that could previously have inhibited their inputs on TCAT groups
- Participants can relate their experience in ways that contribute to *systemic change*, in addition to enhancing the understanding of non-cancer sufferers in attendance
- TCAT project representatives recognise and understand their part in the wider TCAT structure, as well as their access to support from others performing similar roles within TCAT (including the Cancer Experience Panel)
- Participants understand the importance of their role on TCAT groups and are motivated to help others value that importance.

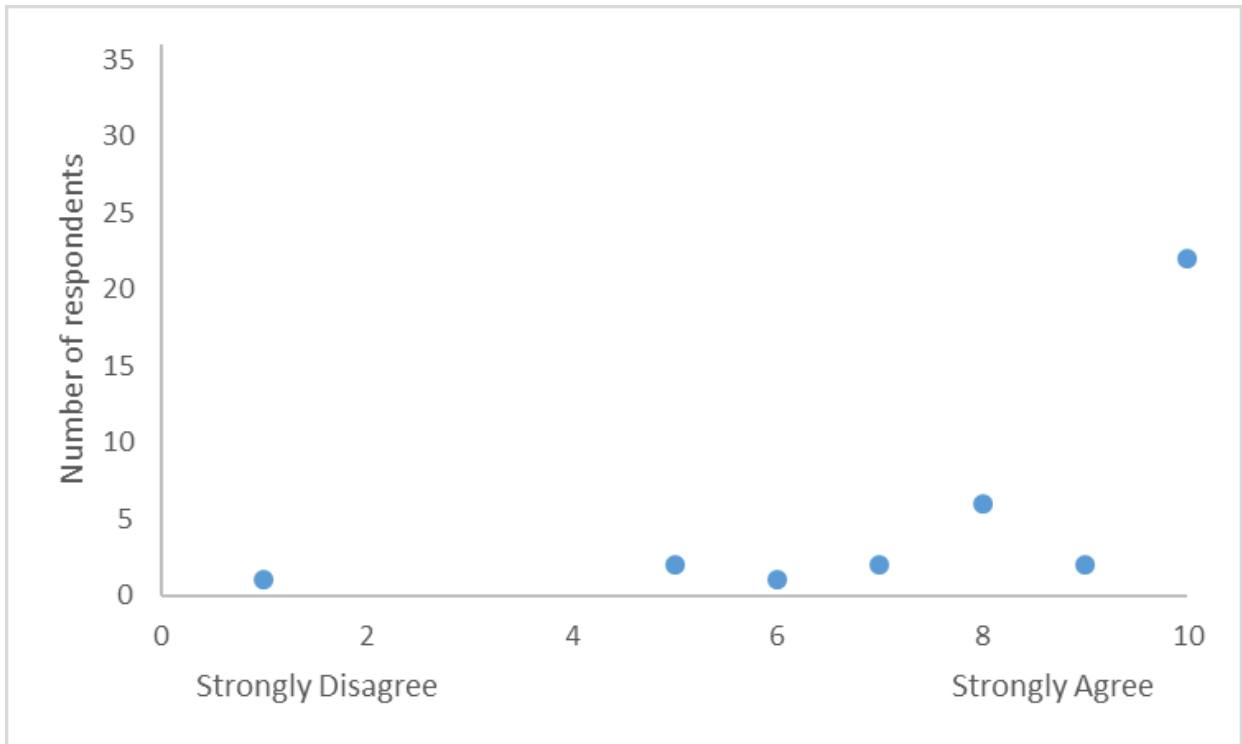
Given available resources, the CEP were able to provide 4 day-long training sessions (2 in October 2015 and one each in September 2016 and April 2017) and a total of 36 people participated.

A potential legacy of the CEP and TCAT is for this partnership approach to the training of involved users to be developed, to include staff and made available more frequently as a rolling programme in different locations.

Positive and Meaningful

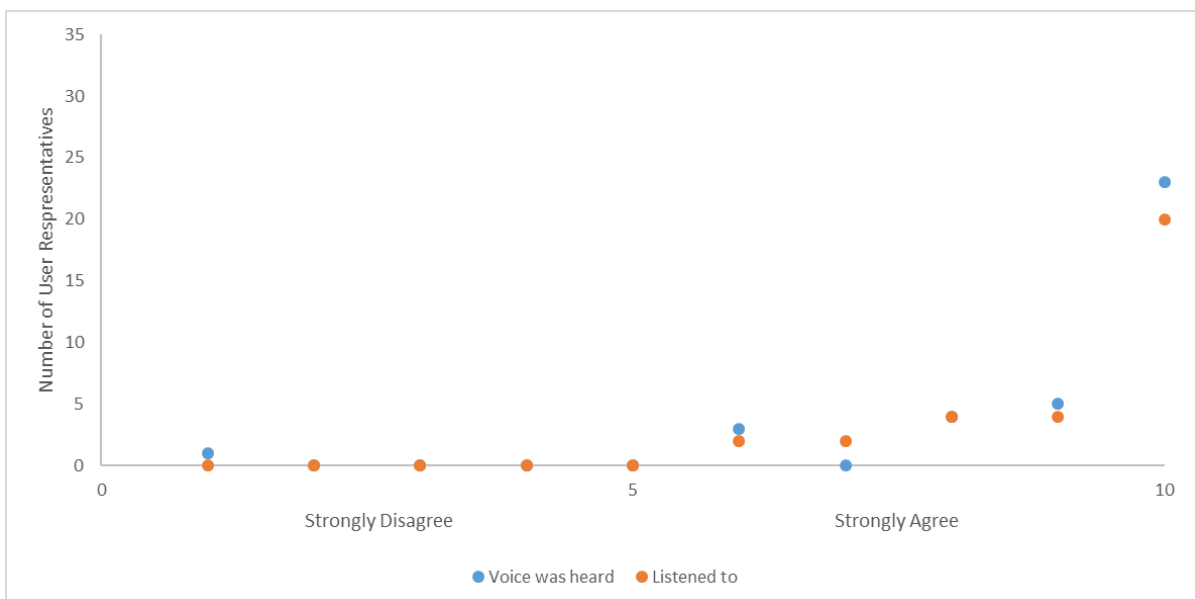
Qualitative analysis of the user representative open text responses from the questionnaire identified the themes of pride, positivity and enthusiasm felt by those affected by cancer involved in the programme. A high percentage also reported feeling that the contribution they were making was valued. However, as the graph below shows - not all those involved in TCAT felt this.

Figure 5: User representative agreement with the statement: My contribution was valued



This mix of experiences was also found among user representatives within local TCAT projects in relation to the statements “I have the opportunity to have my voice heard” and “I am listened to.”

Figure 6: User representative agreement with the statements: “I have the opportunity to have my voice heard” and “I am listened to.”



Local projects and wider stakeholders reported the value of involving users in their work and displayed a high level of commitment to making it as positive and meaningful as they could.

Meaning for user involvement comes from users feeling that their involvement has made a difference. Participants at the conference and local user representatives were asked to indicate where on the continuum they considered they were. Local project representatives populated the continuum from right to left (see Figure 7). A similar spread of involvement to influence was given by those users attending the CEP National Conference (see Figure 8).

Figure 7: Location of local user representatives on involvement continuum

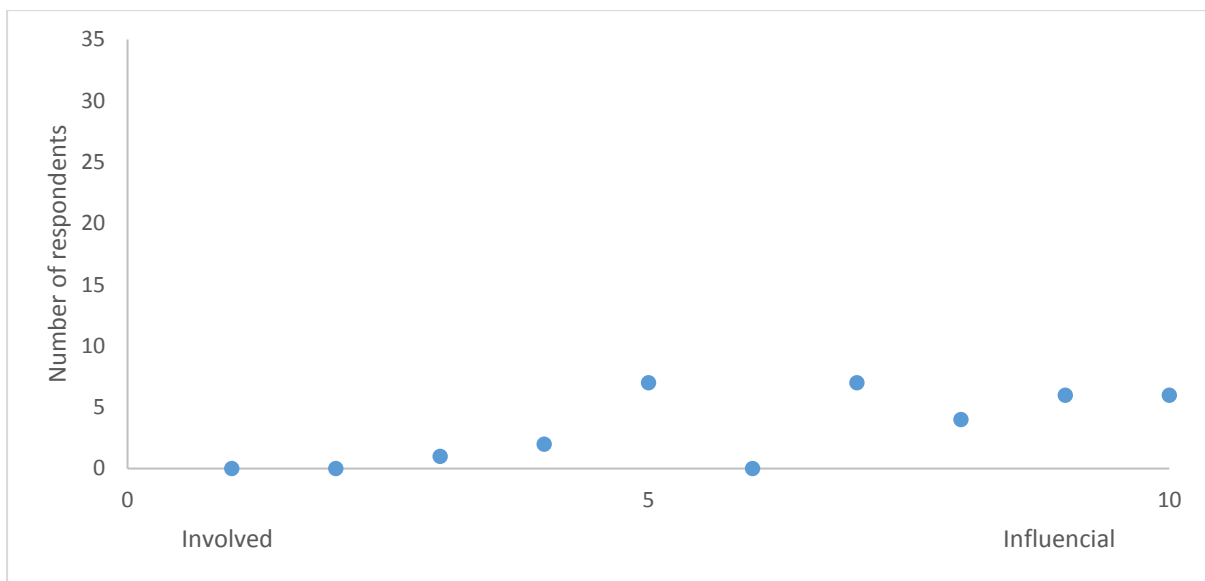
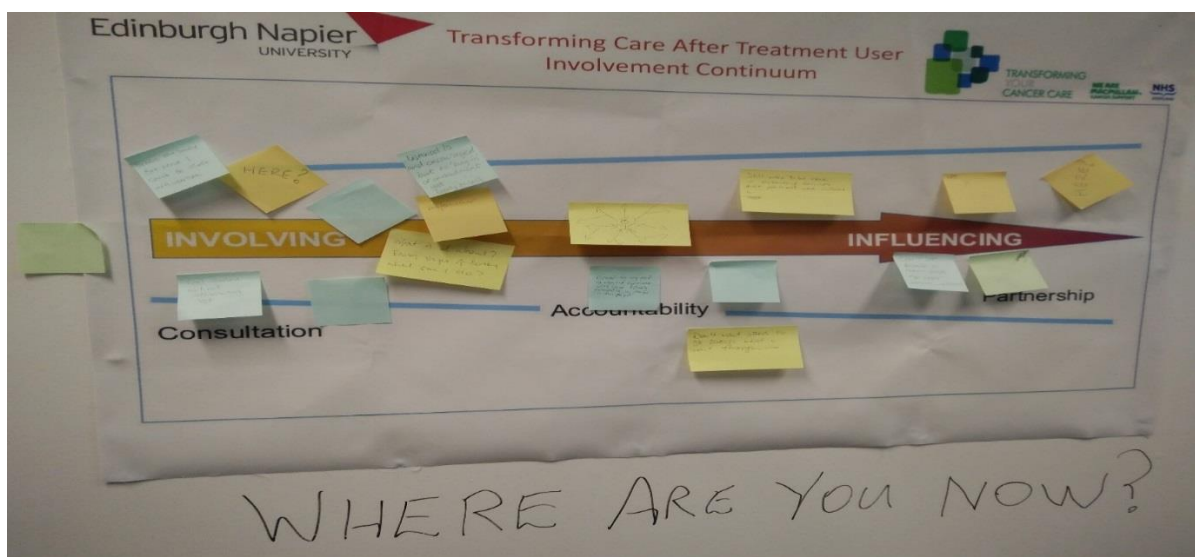


Figure 8: Location of conference participants on involvement continuum



Across local TCAT projects there are examples of activities and events where the contribution made by people affected by cancer has made a difference. Overall the most common response to the question 'what difference has user involvement made' was generic and non-specific. However, in saying this the benefit, insight and value of this 'presence' and contributions made was highly regarded.

Areas of more specific 'influence' were described most frequently in the following activities.

- Providing feedback on specific aspects of local projects (language of leaflets, referral routes, content of well-being events)
- Educating professionals about the experiences of cancer and where services and service responses could be improved, by raising awareness of issues faced by survivors
- Participating in well-being events held locally
- Raising awareness of TCAT both locally and nationally
- Interacting and communicating with other agencies/user forums

Measuring the extent of 'influence' is not possible but local user representatives and wider stakeholders spoke often of the intangible influence that results from a patient telling their story and practitioners and service commissioners listening and better understanding these experiences.

"I hope that my input may help to improve understanding of the problems faced by people in recovery and employers"

"I had combined Chemotherapy and radiotherapy treatment for lung cancer in 2012 and I felt that my experiences of care during and after treatment might be shared".

"I believe that the project has been successful in helping others and in creating awareness among professionals and providing a valuable drop-in service."

"TCAT Health and Wellbeing events always included a patient sharing their own experience of cancer with participants. This was by far the most moving and meaningful part of the events. There is always a lot of information at these events but people will always remember how something made them FEEL overall. This form of influence can never be underestimated. A wealth of wisdom and empathy is born out of a life touched by cancer and professionals would be wise to listen to this wisdom more carefully"

Embedded

The picture found is one of increasingly positive perspectives on the extent to which the patient voice is part of TCAT. In 2017, 54% of wider stakeholders reported “to a great extent” compared to only 30% in 2015. A similar change in response (from 35% to 50%) was found in relation to the patient voice being part of the regional arms of the national programme. See Tables 3 and 4.

Table 3: Extent to which the patient voice is part of NATIONAL TCAT programme

	2015		2016		2017	
	N	%	N	%	N	%
To a great extent	7	30	27	40	20	54
Somewhat	12	52	34	50	16	43
Very little	3	13	6	9	1	3
Not at all	1	4	1	1	0	0
Total (N)	(23)		(68)		(37)	

Table 4: Extent to which the patient voice is part of REGIONAL TCAT programme

	2015		2016		2017	
	N	%	N	%	N	%
To a great extent	9	35	21	32	20	50
Somewhat	13	50	38	58	17	43
Very little	3	12	5	8	3	7
Not at all	1	4	1	2	0	0
Total (N)	(26)		(65)		(40)	

The percentages reporting that the patient voice was part of local TCAT projects “to a great extent” was consistently higher than for national and regional ‘embedding’ across the three years. This too has risen since 2015 - with 51% giving this answer in the first year compared to 59% in 2017.

Table 5: Extent to which the patient voice is part of the LOCAL TCAT programme

	2015		2016		2017	
	N	%	N	%	N	%
To a great extent	18	51	46	52	27	59
Somewhat	16	46	36	40	15	32
Very little	1	3	5	6	4	9
Not at all	0	0	2	2	0	0
Total (N)	(35)		(89)		(46)	

It would appear that the inbuilt emphasis and intent of TCAT to enhance user involvement, has contributed to the role of the patient voice developing and increasing over the years. This is particularly evident locally where the priority of user input was mandated to local projects and supported by the CEP and TCAT User Involvement Manager. However to ensure and embed user involvement and influence, a legacy of TCAT must be that everyone continues to aim high.

Conclusion

Within the sources used, the four most frequently made suggestions for developing user involvement across and beyond the TCAT programme are given below.

- Ensuring the **dedication of resources, support and capacity** for user involvement activities within services and projects. This will increase the likelihood of it being done 'well' and early enough in project lifespan to maximise influence.
- **Increasing the number of users** involved. This would involve the provision of a range of involvement activities, understanding of the capacity of people affected by cancer (PABC) to be involved, flexibly and intermittently perhaps and ensuring wide publicity of opportunities to be involved. This would also contribute to broadening the patient voice beyond individual representatives.
- **Formalising and mandating support and training** for individuals locally, regionally and nationally.
- **Establish ongoing opportunities for PABC to have their story heard.** Users involved in TCAT stressed the need for those responsible for cancer services in Scotland to keep talking to patients and their families and more importantly to keep listening.

The programme has undertaken valuable groundwork and provided a framework within which others can maximise the involvement of people affected by cancer in service planning and delivery, sustain and creatively develop user involvement and, whilst facilitating and encouraging increased influence. The continuum model and its components should be disseminated widely and consulted upon further to gain consensus and encourage their use.

A number of user representatives and projects warn against complacency or seeing the job of user involvement/influence as 'complete' or 'adequate' within the time limited pilot projects or programme. Many users who have been involved question - what will happen when TCAT finishes? Others considered that intensified commitment and action was required as it was 'early days' for user involvement in cancer services and more emphasised the need for what they described as "less talk, more action".

“I think it is beginning to make a difference but we are not there yet”

“Involvement is still in its infancy - true patient led scrutiny of services and partnership working is still largely undervalued and misunderstood by many professionals”

TCAT now has to ensure momentum. To assist in this, during 2018, the TCAT Cancer Experience Panel will disseminate further key learning points, to further awareness of the principles and practice that patients and carers who were involved in TCAT have indicated were important to successful, meaningful involvement throughout the programme.

The CEP's main role during the remainder of TCAT will be to disseminate these key messages. The aim is to provide a reference beyond the confines of TCAT, for the benefit of those who use services, as well as those who run or commission them. This Bulletin and the CEP Key Messages will contribute to increasing the voice of users in health and social care service provision and development.

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