Transforming Care After Treatment in Ayrshire and Arran

Phase 1 Project Summary

Contents

This is a brief summary collating information from various evaluation streams. A full report produced by NHS Ayrshire and Arran's Public Health Department is available on request from Debbie.Provan@aapct.scot.nhs.uk.

Background

This is the final report from a two-year evaluation of NHS Ayrshire and Arran's Phase 1 Transforming Care After Treatment (TCAT) project.

The TCAT programme is a partnership between the Scottish Government, Macmillan Cancer Support, NHS Scotland and local authorities which supports a redesign of care following active treatment of cancer. The five year programme launched in 2013, aims to support and enable cancer survivors to live as healthy a life as possible for as long as possible.

Following a call for funding, NHS Ayrshire and Arran worked with local patients and other partners to develop an application which sought to meet the TCAT programme's aims through service re-design and co-production. The proposal was accepted, and in November 2014 the TCAT team began to introduce a number of initiatives which would support holistic care throughout the extended cancer pathway. In brief NHS Ayrshire and Arran's breast cancer clinical nurse specialists (CNS) now offer a holistic needs assessment (HNA*[1]) to people recently diagnosed with breast cancer, and those who are about to finish their active treatment. The same patients are also invited (opt-out system) to attend a post-treatment community Health and Well-being Clinic (HWBC) where a further HNA is offered; and they can access the newly developed Healthy and Active Rehabilitation Programme (HARP) which has replaced the planned cancer-specific Active Recovery programme. Colorectal, Head and Neck and Gynae-oncolgy CNSs have also embraced the TCAT approach, adopting Treatment Summaries (EoTS*[2]) and the HNA (at the end of treatment or during follow-up appointments depending on tumour site and pathway). As a result their patients can also access the HWBC and many are routinely referred to the HARP programme or signposted to other community assets which meet individual needs.

At the same time as the TCAT project was being implemented NHS Ayrshire and Arran's Breast Cancer Team changed their model of follow-up to reflect risk stratified care. Instead of continuing to follow-up every breast cancer patient at an annual surgical clinic over a 10 year period, the team would discuss each patient at MDT and determine whether the patient would be reviewed in clinic annually (clinic led follow-up pathway) or enter into a new "patient led follow-up pathway". Those on the "patient-led" pathway would be defined as such if they were considered able to self manage and to report back to services as and when required. Both pathway groups continue to receive an annual mammogram with rapid access back to surgical if/when needed. The TCAT project has facilitated this shift by ensuring patients have the knowledge, skills and support required to self-manage their condition.

Ayrshire's new holistic approach to care, spanning pathways and care sectors, has been achieved through partnership working and a shared vision. Key partners include Macmillan Cancer Support, Ayrshire Cancer Support, North Ayrshire Council, South Ayrshire Council, East Ayrshire Council, KA Leisure and the TCAT Patient and Carer Panel. The project has received wide-spread recognition illustrated by some key achievements. For example the extended TCAT team were finalists for the Ayrshire Achieves 'Team of the Year' award in

2016 and the TCAT Patient and Carer Panel were also finalists in the 'Volunteer of the Year' category. The project also won the 'Macmillan award for leadership and innovation in cancer rehabilitation' at the 2016 Advancing Healthcare Awards.

From a policy context there is a clear clinical and social recognition of the need to ensure that people affected by cancer receive personalised, coordinated and timely support across health and social care services. Ayrshire's TCAT project is designed to provide exactly this type of support and aims to improve the outcomes of people affected by cancer across Ayrshire and Arran.

In order to provide a deeper understanding of the impact of this project and provide evidence for future planners and commissioners of comparable services, a robust evaluation plan was developed during the project planning stage. Whilst some qualitative data was 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 provided 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. This entailed sending a questionnaire to all patients diagnosed with breast cancer in 2013/2014 and all patients diagnosed with colorectal cancer in 2014/2015.This final report summarises the findings of all of these processes.

Aim

The purpose of this evaluation is to provide independent evidence for the impact of NHS Ayrshire and Arran's Phase 1 TCAT Project.

The project set out to focus on breast and colorectal cancer and to provide a streamlined, effective, efficient, and person-centred service through the delivery of complete packages of care; ultimately improving cancer outcomes and quality of life whilst promoting ongoing health and well-being. As such this evaluation will address the following question:

> ***How does the new TCAT pathways improve quality of care and outcomes for people living with cancer?***

Method

This question is considered from three different perspectives:
- The individual level (eg people affected by cancer),
- The service level (TCAT project), and
- The cultural level (health and social care agenda).

The outcomes the project set out to achieve are specified in its 'logic model' (Appendix 1). The logic model outcomes identify goals. For example, it contains the following statement:

> *Patients attend health and wellbeing clinic(s) and rate highly the support provided*

Project success is therefore measured against the degree to which this and the other outcomes have been met. There are 12 logic model outcomes in all, and they are categorised as short-term or medium-term. Additional objectives attached to the project but not covered by the logic model goals are also reviewed to further measure success. For example:

- *Create and promote a map of services which facilitates easy navigation of services by patients and clinicians*
- *Introduce and embed an end of treatment summary*
- *Develop existing services and limit/fill gaps by introducing new models of care, improving skill mix and creating tiered services which directly relate to identified needs*
- *Share progress and learning locally and nationally to enable spread and challenge cultural thinking.*

In order to measure the individual level outcomes a range of methods were used including analysis of routine data, questionnaires and interviews. To measure the service level outcomes, patient and staff feedback was used and outputs considered. To measure the cultural perspective the same data were analysed from the perspective of the wider health and social care agenda.

Results

The overall results are extremely encouraging. There is strong evidence that the vast majority of logic model outcomes are being met. Some key results are highlighted below.

Limitations and dataset

Whilst the project has managed to incorporate head and neck and gynaecology pathways this was not part of the original project scope and late inclusion limited the opportunity for evaluation due to timing and small numbers. In light of this only activity data and a small treatment summary audit in head and neck cancer are incorporated in this evaluation. The significance of colorectal pathway data is also limited by the small number of patients and the response rate. As a result this report will focus on breast cancer with only minimal reporting of other tumour sites when breast data is missing i.e. in relation to Treatment Summaries.

Individual level

276 patients were seen by the project between 2nd September 2014 and 28th June 2016. **86.2% had breast cancer**, 12% colorectal cancer, 1.4% gynaecological cancer and 0.4% head and neck cancer. **Female patients** were the largest group of participants, **making up 92%,** which is to be expected due to the high proportion of the patients diagnosed with breast cancer. The age range of patients was 27-89, **with 91.3% falling between the ages of 40-79**. Ethnicity data was missing/not known for 26 patients, of the remaining 250 patients **98.4% were "White, Scottish".** Economic data was missing/not known in 178 patients; of the remaining 98 patients, 46.9% were retired.

A variety of Recovery Package*[3] products were introduced to various tumour pathways as part of the TCAT project. This is summarised in Table 1.

Table 1: Products Introduced by Tumour Sites

Tumour Site	HNA	EoTS	HWBC	Access to Rehabilitation Prog.
Breast	Y	N	Y	Y
Colorectal	N (Trialling)	Y	Y	Y
Head & Neck	Y	Y	Y	Y
Gynaecology	Y	Y	Y	Y

A more detailed visual representation of the work which has been undertaken is shown in Appendix 2.

The HNA of choice was the Cancer Concerns Checklist. **641 HNAs were completed** between 2nd September 2014 and 28th June 2016. 597 of those were classified as breast, 37 colorectal, 4 gynaeoncology and 3 head and neck cancer. On average, people identified **5.4 concerns** each with the **top three concerns being Tired/exhausted/fatigued; Worry/fear or anxiety; and Hot flushing/sweating**. This is significant as findings from the questionnaires distributed to patients on the baseline (pre-TCAT) pathway indicated that patients with more than one concern were less likely to seek help than those with only one concern. Patients on the previous pathway (which did not incorporate the HNA) also reported that they had significantly more concerns than they sought help for with 46% of people with concerns not seeking any help.

HNAs were carried out at different time points in the pathway i.e. soon after diagnosis, at end of treatment (EoT), or at the HWBC 6-8 weeks after treatment. This enabled team members to understand how concerns change over time (Table 2) and gave team members an opportunity to re-visit agreed actions from previous care plans. The HNAs and care plans completed soon after diagnosis and at end of treatment were incorporated into a busy oncology clinic which made it difficult to identify how long the assessment and care planning process took. However, this was the main focus of the HWBC consultation and 73.4% of these consultations were completed in 20-30minutes.

The **majority of concerns raised via the HNA were discussed with general advice given (n=263) and information given (n=159). 55 onward referrals were made to over 11 agencies.** The most frequent referral by organisation was to Ayrshire Cancer Support. Ayrshire Cancer Support is a local third-sector organisation which offers a range of services from mindfulness to support groups, complementary therapies to counselling. This range of services met a wide-range of needs identified and this explains the frequency of use.

Table 2: Top 3 Concerns and Information Needs of Breast Cancer Patients by Pathway Stage

	Diagnosis (% of patients)	EoT (% of patients)	HWBC (% of patients)
No. 1 Concern	Tired/exhausted or fatigued (38%)	Tired/exhausted or fatigued (43%)	Tired/exhausted or fatigued (53%)
No. 2 Concern	Worry, fear or anxiety (36%)	Hot flushes/sweating (39%)	Hot flushes/sweating (38%)
No. 3 Concerns	Pain (28%)	Sleep problems/nightmares (24%)	Worry, fear or anxiety (32%)
No. 1 Info. Need	Exercise and activity (27%)	Diet and nutrition (13%)	Complementary therapies (25%)
No. 2 Info. Need	Diet and nutrition (26%)	Exercise and activity (11%)	Exercise and activity (22%)
No. 3 Info. Needs	Complementary therapies (21%)	Complementary therapies (10%)	Diet and nutrition (12%)

Looking at the HWBC from its inception on January 25th 2015 until July 31st 2016 the following stats were recorded:

Table 3: Attendance, Did not attend and cancellation rates of the HWBC per tumour site.

	Breast	Colorectal	Head and Neck	Gynaeoncology
Invited	210	77	10	8
Attended	127 (60.5%)	43 (55.8%)	5 (50%)	5 (62.5%)
Did Not Attend	23 (11%)	7 (9.1%)	0	1 (12.5%)
Cancelled	60 (28.5%)	27 (35.1%)	5 (50%)	2 (25%)

On average 59% of those invited attended the HWBC whilst 31% cancelled and 10% did not attend.

In order to help establish the impact of the HNA and HWBC, patients on the previous and new TCAT pathways were asked about their concerns approximately 3 months after their treatment finished/the health and wellbeing clinic. Table 4 illustrates the results.

Table 4: Concerns reported by breast cancer patients: old vs. new pathway

Concern	Previous Pathway	TCAT Pathway
Fear of recurrence	70%	37%
Physical	64%	56%
Practical	29%	20%
Lifestyle	29%	27%
Emotional	26%	29%
Spiritual	2%	5%
Family	24%	15%
Diagnosis and treatment	22%	12%
Body image	24%	10%
No concerns	7%	27%

Satisfaction with post-treatment support and knowledge of named breast care nurse was also compared across the two pathways:

Table 5: Satisfaction of post-treatment support: old vs. new pathway

Type of Support	Previous Pathway	TCAT Pathway
Post treatment support from GP practice completely met my need	38% (18% had no need for this support)	42% (19% had no need for this support)
Post treatment support from hospital staff completely met my need	48% (17% had no need for this support)	56% (17% had no need for this support)
Named breast care nurse	82% (6% did not have a named breast care nurse and 12% did not know)	90% (10% did not respond)

This data as well as the two statistics below illustrate that in terms of satisfaction with the service, **feedback is almost entirely positive for the new service**:

- **89%** of patients rated the HWBC as very or fairly helpful
- **72%** of patients attending the HWBC found the HNA helpful

In addition to these quantitative responses, respondents reported that the **HWBC allowed them the space to discuss concerns about their wellbeing and raise issues around emotional and lifestyle difficulties**. Several patients felt it had given them **time to discuss concerns and find out about the support that was available** to them locally to meet more holistic needs particularly complementary therapies. A few people also indicated that **it was good to know they had not been forgotten** whilst another stated that **it was good to talk to someone neutral** and not always family.

> *"[The HWBC] Offered good opportunity to talk about concerns as felt low at end of treatment period after high level of contact with professionals. Helped me to take steps to use help available"*
>
> **Quote from Pt re. the HWBC**

> *"It was good to be able to talk to someone neutral at times it can be difficult. My son is about to be married, has his own life but still very upsetting and difficult for everyone coping with this diagnosis"*
>
> **Quote from Pt re. the HWBC**

Onward referral rates as a result of the HNA were reported previously and patient feedback indicated that their use of other services was fairly low; however when services were used, the majority of patients reported high levels of satisfaction.

The breast team and the health wellbeing practitioner leading the HWBC both trialled the electronic HNA. As a result they needed to print care plans before being able to issue them to patients. This presented some logistical problems due to availability and location of printers in busy areas and often meant care plans would have to be printed at a later date and posted to patients. As a result the breast team would ask if they wanted a copy of the care plan and would only send it to those who accepted this offer. The HWBC routinely

posted care plans to the patient, and if permission had been granted to their GP, following the HWBC. Despite this only **37% of patients reported that they received a care plan at the HWBC**, whilst 26% did not remember and 6% did not respond. Given this routine practice of posting care plans, it is questioned whether part of the reason for this low statistic is down to language and understanding of what a care plan is. However, this should be investigated further.

Of those who received their care plan **17% reported following the care plan completely, 38% mainly followed the care plan and 17% partly followed it**. 28% reported that no action was required by them. The low number of people following the care plan 'completely' also requires further investigation and raises questions about the approach to care planning i.e. is this clinician led or truly co-produced, and what are the barriers/facilitators to implementation?

Integrating all of the results presented above into the logic model shows that the following objectives are already being met or positive progress has been made:

- Patients attend health and wellbeing clinic(s) and rate highly the support provided
- Patients on patient-led follow-up rate highly the follow-up process
- Patients are aware of relevant information and support services and rate highly the information provided about these services
- Patients access support services they have been signposted to and rate highly the support provided
- Patients adhere to their Care Plans
- Patients do not feel abandoned by the health service
- Patients feel their needs, identified by their HNA, are being met

Service level

This element of the evaluation focused on the frequency, timing and location of the HWBC, and its ability to support the delivery of successful outcomes. Key outputs were also considered (i.e. the Support Service Directory, Active Recover/HARP and the TCAT Patient and Carer Panel), as was the impact of the Treatment Summary which was evaluated through patient feedback and a small audit of GPs and patients.

To help establish whether the timing and location of the HWBC had any bearing on non-attendance 31 patients who cancelled their HWBC appointment and 20 who did not attend were issued with a short self-completion questionnaire (all patients had a diagnosis of breast cancer). Of those, 21 (68% response rate) and 11 (55% response rate) patients responded respectively. A higher percentage of respondents who cancelled their HWBC appointment were from the less deprived areas, while individuals who did not attend their appointment (without cancelling in advance) were mainly from the most deprived quintile.

From this small sample of people that cancelled or did not attend their appointment, **the majority did not think that changing the timing of the HWBC appointment would have affected their choice not to attend. Most responders (21) indicated that they did not think that the HWBC appointment was necessary because they were already receiving all of the support that they needed.** However, four individuals indicated that they did not feel well enough to attend.

These responses were validated by comparing concerns data at the end of treatment with the above responses. This process revealed that 35% of those who cancelled or did not attend their HWBC had no concerns at the end of treatment, whilst a further 45% of patients had very few concerns (4 or less). These findings are positive and suggest that the level of support received during active treatment is sufficient for a large number of patients. However it should be noted that this leaves 20% of patients with a higher number of concerns and on further investigation these same patients tended to be from the most deprived quintile. This has implications for health inequalities and as such steps should be taken to engage with this group.

In order to further support the HNA and care planning process it was recognised that a directory of support services would be beneficial. A directory would assist clinicians by indicating the availability of local services and access routes; and support patients by providing first line advice for each of the problems listed on the Cancer Concerns Checklist and by listing local, regional and national services/information. NHS Ayrshire and Arran's Macmillan Consultant Clinical Psychologist was able to provide a basis for the Directory through gaining permission from NHS Bristol to adapt their existing Cancer Support Service Directory. The TCAT team then worked together with local partners to populate the template with local information, amending categories to reflect the Cancer Concerns Checklist content. The directory was then made available to staff through NHS Ayrshire and Arran's intranet and more widely through Ayrshire Cancer Network (a local internet site managed by Ayrshire Cancer Support and originally funded by Macmillan Cancer Support). To maintain its integrity the directory is updated on a 6-monthly basis.

By sharing the learning from the project, the **Support Service Directory has been picked up by a number of other areas. It has also been instrumental in the development of the National Support Service Directory** being developed by NHS 24 in partnership with Macmillan Cancer Support which should enable the public to find quality assured and local services close to them which meets their needs.

Following previous local work which looked at the importance, availability and impact of advice and support focused on physical activity and eating well, a gap in service provision was identified. As a result the TCAT Project Lead worked with local leisure services to provide a 12 week diet and exercise programme. Through a process of engagement with the TCAT Patient and Carer Panel and other volunteers, the programme was named Active Recovery and promotional leaflets were developed. Uptake was slow despite engagement with clinical teams, promotion via the HWBC and regular requests for information on diet and physical activity from patients via the HNA. Then early in 2015 the TCAT Project Lead and Macmillan Cancer Nurse Consultant began working with local colleagues to develop a tiered Multi-morbidity Rehabilitation Programme (latterly called HARP); and people with a diagnosis of cancer and at least one other co-morbidity were able to access this programme from late 2015. As HARP was able to offer a wider variety of classes across a greater number of venues than Active Recovery, it became the preferred programme and as a result HARP is now promoted to patients in place of Active Recovery. Evaluation of HARP is ongoing however **more than 180 people with a diagnosis of cancer have accessed the programme to date.** This figure is significantly greater than that achieved by previous services; however given the number of people identifying "Exercise and activity" and "Diet and nutrition" as an information need via

the HNA we may need to give further consideration as to how services are promoted to patients and how rehabilitative approaches such as these are embedded within pathways to ensure maximum engagement and promote outcomes.

A dedicated patient and carer panel was established to ensure meaningful engagement of people affected by cancer in the design and delivery of the project.

Early on in the delivery of the HWBC it was recognised that uptake and attendance was lower than expected. Only 57% of invitees were attending and there were a significant number of people failing to attend without notification (20%). In response, the TCAT Patient and Carer Panel members suggested a number of changes to the information provided to patients before the clinic and the administration processes undertaken. They recommended:

- Developing an information leaflet about the clinic which should be given to patients by their clinical nurse specialist at their final oncology appointment thus showing continuity of care and potentially encouraging attendance through advocacy by clinical teams
- Editing the pre-clinic invitation letter sent to patients following cessation of their treatment to better explain the purpose of the clinic and what happens during an appointment
- Introducing a reminder phone call approximately 1 week prior to an appointment to ensure people managing multiple appointments and suffering from memory problems do not forget about their appointment.

The impact 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 reducing from 20% to 10%**
- **User cancellation rates increasing from 24% to 31%.**

Together non-attendance reduction and advanced cancellation of appointments allowed staff to be more efficient. This also increased the availability of appointments for those in need. The value of this work was further justified as feedback from early participants of the HWBC articulated the need for clearer information about the clinic for example:

> *"If you were taking this forward, I definitely, probably think that you need to be clear about what it was because when the first appointment came through I thought, Oh I wonder what that's about, I wonder what I'm going there for… I wasn't really sure what the purpose of it would be."*

> *"What we first said was what's this about? We weren't really sure and the only reason we went was as I said someone we knew had said it was really helpful"*

Feedback from participants of the Patient and Carer Panel also expressed how valuable their contribution TCAT has been:

> *"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 within 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."

"It's great that people are living longer now-a-days 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 very heard and included in discussion and decision making. Communication has been excellent. My long-term hope is that everything that TCAT has achieved can become sustainable practice."

The NCSI/Macmillan template was used when introducing the Treatment Summary. Initially CNSs used a 'Word' version to type it up before printing for patients and emailing (via secure clinical email) to the GP. Some CNSs are now dictating the content for medical secretaries to type using 'Winscribe'. This limits the impact on clinical time but it is recognised that this is not an ideal solution. Attempts have been made to try to adopt NHS Forth Valley's TSum system which has some intelligence built in (sections are pre-populated depending on diagnosis, treatment intent and treatment) and allows transfer of information to GPs by clinical email; as it is believed this would further reduce the impact upon clinic time and allow quicker transfer of information across care sectors. However after review by eHealth colleagues another software program which would allow us to embed some of the outputs of TSum, but better integrate with existing local systems, is now being reviewed by the organisation.

In order to ascertain how useful the Treatment Summary is to practice, the views of GPs were sought by issuing 19 GPs who had received a Treatment Summary by the Head and Neck CNS with an electronic questionnaire. 31% of GPs responded and all feedback was positive i.e. **the Treatment Summary:**
- **Aided discussion with patients (n=5)**
- **Supported completion of insurance forms, Key Information Summaries and Anticipatory Care Plans (n=5)**
- **Supported decisions about the patient's condition, care, or management (n=2),**
- **Helped to understand the patients diagnosis, treatment and ongoing needs (n=3)**
- **Improved communication with the patient (n=2)**

One GP went on to articulate one of the problems the Treatment Summary aims to solve, highlighting one of its many benefits i.e. pulling together key information into one short summary:

"I have 33 bits of paper about this (on top of another 10 or so about other things since the diagnosis). Primary Care is drowning in Secondary Care overflow."

21 head and neck cancer patients who received a Treatment Summary were sent a postal questionnaire to ascertain their views. 3 responses were received (14% response rate). **All found the Treatment Summary easy to understand and all had discussed it with their GP or Practice Nurse.** They also believed **the Treatment Summary enabled them to understand the ongoing effects of radiotherapy and encouraged them to take actions**

which supported their ongoing health and well-being e.g. accessing services, maintaining a healthy weight and exercising despite fatigue.

25 questionnaires distributed as part of the Public Health Department's evaluation process were sent to patients with a diagnosis of colorectal cancer and a question about the Treatment Summary was asked. 14 patients responded (56% response rate), and 13 of those recalled receiving a Treatment Summary (one did not know). **61.5% of those who received a Treatment Summary had discussed it with their GP or Practice Nurse.**

From the feedback it is clear that some degree of flexibility is required to meet individual needs, but on the whole **the HWBC meets the needs of those requiring additional support and information at the end of treatment and the products put in place** (HNA, Treatment Summary and HWBC) **support people to live well after treatment**.

As well as the logic model outcomes discussed in the 'Individual' section, this 'Service' section illustrates that the following additional objectives are also being met:

- *Create and promote a map of services which facilitates easy navigation of services by patients and clinicians*
- *Introduce and embed an end of treatment summary*
- *Develop existing services and limit/fill gaps by introducing new models of care, improving skill mix and creating tiered services which directly relate to identified needs*

Cultural level

NHS Ayrshire and Arran's TCAT project has re-enforced existing partnerships with many local organisations and has supported the development of new and existing services. It has achieved this through actively networking with relevant partners and creating innovative solutions where necessary to better support people. For example, by working with Ayrshire Cancer Support it was possible to provide an increased number of mindfulness classes and prevent a waiting list from forming; and by working with multi-disciplinary and multi-agency teams to develop Active Recovery and HARP access to rehabilitation services was improved with classes now being provided closer to people's homes. A large number of generalist/specialists in areas other than cancer have also been trained and up skilled in cancer resulting in a wider workforce being able to confidently work with people affected by cancer.

In addition to the above the extended project team have worked tirelessly to spread learning by:
- Contributing to national and regional 'TCAT Learn and Share' events, and organising and hosting a local event specifically focused on this project which attracted wide-spread interest,
- Presenting their work at various national conferences i.e. 'NHS Scotland Conference 2016' and 'RCN Research Conference 2016'.
- Submitting two journal articles with one being accepted for 'Cancer Nursing Practice' and one under peer review with 'Primary Healthcare', and
- Routinely attending and participating in the Regional Implementation Steering Group.

These examples illustrate how the TCAT project has worked to create a cultural change and helped to place the individual at the centre of their care.

As well as the goals discussed in the previous sections this section showed that this additional objective is being met:

- *Share progress and learning locally and nationally to enable spread and challenge cultural thinking*

Discussion

This evaluation exercise has provided a wealth of information that helps to shed further light on the challenges and problems that people experience after their treatment for breast or colorectal cancer has finished in Ayrshire and Arran. It also provides insights in to how people behave and respond to these challenges, drawing on their own reserves and what is available around them for support, including statutory and non-statutory services. Finally it provides a range of opinions and feedback on the services provided, and specifically the new HWBC, the HNA and Treatment Summaries.

The project results suggest that despite a hypothesis that a change in follow-up model (i.e. clinic-led to a combination of clinic-led and patient-led) could increase feelings of abandonment and result in a higher degree/number of unmet needs, with the right support at an early stage, post-treatment needs can actually be reduced. The knock on effect of which is a reduction in the number of routine follow-up slots required (may be as many as 2500 per annum (based on 350 new patients per year being followed up annually over 10 years and 70% moving to patient-led follow-up) and allows for reallocation of these to new patients, or those with complex needs and those unable to self-manage.

The results of the project also show clear progress against all of the logic model outcomes and the additional objectives set out in the project plan. As a result it is clear that NHS Ayrshire and Arran's TCAT project has delivered what it set out to achieve and that it has provided evidence of person- centred, proactive, interagency care which has been developed through co-production.

The biggest challenges faced by the project were as a result of systems, processes and culture. Due to the short timescales of the project, pace was of the essence however, complex systems (for example hospital clinics, IT systems and multi-disciplinary working) and processes (for example recruitment and HR processes) mean this was not easy. It must also be remembered that part of the rationale for this project, and the TCAT programme as a whole, was the pressure that is being placed on health and social care as a result of increased cancer numbers, treatment advances and improved survivorship. Change in this environment can be exceptionally challenging, and whilst work to truly embed changes and spread good practice remains to be done, outstanding progress has been made. This illustrates the drive and commitment of staff, patients and carers involved in the delivery of this project.

Conclusion

NHS Ayrshire and Arran's TCAT project is helping to change the way services are delivered;

this is benefitting patients, carers, staff and local organisations as a whole. The approach is also delivering key strategic objectives; including some of those outlined in Scotland's Cancer Strategy "Beating Cancer; Ambitions and Action" and the National Health and Wellbeing Outcomes (specifically outcomes 1-5 and 7-9). In light of this it is recommended that the model as a whole continues with some key considerations and recommendations being addressed over the next year to embed the approach in routine practice and secure its sustainability.

Further Considerations and Recommendations

- Holistic needs assessment and care planning during and after treatment should continue and be introduced in tumour groups who do not currently have access. Care plans should also be routinely issued to patients upon completion and should be created in partnership with patients to ensure they are useful and meet needs/support the patient going forward.
- Treatment Summaries should continue and be introduced in tumour groups who do not currently have access.
- An electronic solution to HNA and Treatment Summary recording and reporting should be pursued and prioritised to ensure good practice continues, communication across care sectors improves and information is stored safely.
- Consideration should be given to the location of the HWBC to ensure they are close to home and in an environment which appeals to users. Additional consideration should be given to the prospect of home visits for those with limited mobility and/or access issues. Locations in third-sector organisation premises (e.g. Ayrshire Cancer Support) may be advantageous, as could Macmillan Cancer Information and Support Service locations and GP surgeries.
- Consideration should be given to the need for additional assessment as a result of high levels of anxiety or depression to ensure the correct signposting/referral is actioned.
- Consideration should be given to the process of offering additional HWBC appointments to those with high levels of need or those with a large number of concerns which cannot be addressed in one appointment.
- NHS Ayrshire and Arran, Ayrshire three Health and Social Care Partnerships and local cancer charities should continue to work with NHS 24 to develop the National Support Service Directory and to make it available locally though existing online resources (i.e. organisational websites). This will help to ensure people have easy access to timely and accurate information and support and thus support self-management.
- Closer working with local voluntary groups and further investigation of the 'Community Connector' model provides opportunity for sustainability, will better support the needs of people with multiple morbidities, and may better engage hard to reach groups. As such this should be pursued and evaluated.
- Further investigation of the economic impact of the project is warranted and the methodology should be considered taking advice from ENU colleagues.
- HARP should continue and move towards self-referral processes and wider advertising. Local staff should promote services such as these at every opportunity in order to support rehabilitation and promote outcomes.
- The benefits of partnerships and coproduction should not be underestimated and the need for a wide variety of services, the appropriate skill mix and

approaches which enable individualised care and supported self-management is illustrated by this project and its outcomes. As such it is recommended that services continue to work together and adapt to meet long-term organisational goals and provide a high quality service to patients, their families and carers.

• Leaders across health and social care should consider the TCAT approach and the individual products, advocating their use and supporting system change to enable this to happen without variation across the organisation.

Glossary

*[1] Holistic needs assessment (HNA) is a structured method of discussing someone's physical, emotional, family, practical, lifestyle and spiritual needs.

*[2] The Treatment Summary is a document produced by secondary cancer care professionals at the end of treatment. It provides key information for GPs i.e. possible treatment toxicities, side effects and/or consequences of treatment, signs and symptoms of a recurrence and any actions. It aims to inform primary care professionals of any actions they need take and who to contact with any questions or concerns. The patient also receives a copy to improve understanding of their condition and to provide a summary to share with other professionals and those of their choice e.g. insurance companies.

*[3] The Recovery Package is made up of the following elements:

- A Holistic Needs Assessment (HNA) and care planning at key points of the care pathway.
- A Treatment Summary completed at the end of each acute treatment phase and sent to the patient and GP.
- A Cancer Care Review completed by the GP or practice nurse to discuss the person's needs.
- An education and support event, such as Health and Wellbeing Clinics, to prepare the person for the transition to supported self-management.

Appendix 1: TCAT Logic Model

Desired Short-Term Outcomes (Patient)	Indicators	Methods
1. TCAT follow-up pathway only Patients attend health and wellbeing clinic(s) and rate highly the support provided	1. Number and type of patients who attended health and wellbeing clinic(s) 2. Number and type of patients who attended more than one health and wellbeing clinic 3. Number and type of patients who did not attend (DNA) a health and wellbeing clinic and reason for this 4. Patient satisfaction rating of the support received	• Analysis of HWP records and demographic patient data • Patient questionnaires and interviews
2. Previous follow-up pathway only (sample of patients) Patients attend follow-up hospital-based breast cancer clinic(s) or are on patient-led follow-up and rate highly the follow-up process	1. Number and type of patients from sample who attended follow-up hospital-based breast cancer clinic(s) or are on patient-led follow-up 2. Patient satisfaction rating of the follow-up process	• Analysis of clinic records and demographic patient data • Patient questionnaires and interviews
3. Patients are aware of relevant information and support services and rate highly the information provided about these services	1. Number of support services relevant to their situations that patients can identify 2. Patient knowledge of the support provided by the services, where the services are located and how to contact the services 3. Patient satisfaction rating of the information received about support services including relevance, format, amount, clarity, timing etc.	• Analysis of patient EHNAs, Care Plans and demographic data • Patient questionnaires and interviews
4. Patients access support services they have been signposted to and rate highly the support provided	1. Number and type of patients who were signposted to support services, what services and the reasons for signposting 2. Number and type of patients who accessed support services, what services and the reasons for accessing 3. Number and type of patients who did not access support services, what services and the reasons for this 4. Patient satisfaction rating of the support received	• Analysis of patient EHNAs, Care Plans and demographic data • Patient questionnaires and interviews
5. Patients adhere to their	1. Number and type of patients who adhered to their Care Plans	3. Analysis of patient Care Plans and

		demographic data
Care Plans	2. Number and type of patients who did not adhere to their Care Plans and the reasons for this	4. Patient questionnaires and interviews
6. Patients feel empowered to take control of their lives	1. Patient-reported confidence levels in relation to taking control of their lives or seeking support services themselves	• Patient questionnaires, including confidence rating scale, and interviews
7. Patients do not feel abandoned by the health service	1. Patient-reported feelings about the support received from the NHS post-treatment	• Patient questionnaires and interviews
Medium-Term Outcomes (Patient)	**Indicators**	**Methods**
8. Patients feel their needs, identified by their EHNAs, are being met	• Patient-reported feelings in relation to their needs and if/how these have been met	• Patient questionnaires and interviews
9. Patients adopt a healthy lifestyle	• Patient-reported description of lifestyle	• Patient questionnaires and interviews
10. Patients are moving towards a quality of life that is acceptable to them	• Patient-reported description and satisfaction rating of their quality of life shows improvement over time	• Patient questionnaires and interviews, including quality of life measure
11. Patients feel the post-treatment phase is supportive	• Patient-reported feelings about the support received from the NHS post-treatment	• Patient questionnaires and interviews
12. Reduced patient reliance on medical services	• Number of clinic visits in intervening year	• Analysis of clinic records and demographic patient data • Patient questionnaires and interviews

Appendix 2: Project Development and Outputs

2013

June — TCAT launch
June — TCAT EOI
Sept — eHNA EOI
Sept — TCAT bid
Dec — CanRehab bid
Jan — TCAT bid accepted subject to amendment

2014

Feb — 1st Steering Group
Sept — Breast cancer risk stratification: initiation of eHNA at diagnosis and end of treatment
August — CanRehab training starts
June — TCAT bid accepted
May — Patient & Carer Panel recruitment
April — EoTS in head & neck cancer
April — Cancer showcase event
Feb — eHNA Project Lead starts

Nov — TCAT project lead & Health & Wellbeing practitioner start!
Nov — CanRehab training ends
Jan — TCAT Administrator starts
Jan — 1st breast patient at HWBC
Jan — Patient & Carer Panel recruitment
Feb — Active recovery begins
March — HWBP replaced
March — 1st Patient & Carer panel meeting
April — Cancer Support Service Directory complete

2015

April — "Macmillan Award for Leadership and Innovation in Cancer Rehabilitation" at AHAs
April — Macmillan eHNA Learns & Share poster (wins 3rd prize)
April — RCN research conference posters
Feb — EoTS in gyn-oncology and HWBC referrals
Jan — Head & neck patients referred to HWBC
Sept — HARP accepts cancer referrals
July — EoTS in colorectal cancer
Sept — Local evaluation begins

June — NHS Scotland Conference Posters
June — Patient & Carer Panel finalists in 2015 Ayrshire Achieves "Volunteer of the Year" category and TCAT Team finalists in "team of the Year"
June — Local & national evaluations ends
Aug — Phase 3 bid submitted
Sept — Local learn & share
Sept — Phase 3 bid accepted
Oct — Paper accepted to CNP
Oct — Final / Evaluation report

2016

Project starts
Learn & Share
Governance
Process
Recovery package