

# Transforming Care After Treatment (TCAT)

# Newsletter October 2015

Welcome to the third edition of the Transforming Care After Treatment (TCAT) newsletter. In total we have 25 projects being supported across phases 1 & 2 of the programme. There is 1 national project, 4 within NOSCAN, 9 in SCAN and 11 in WoSCAN with 13 led by secondary care partners, 8 local authority partner led projects and 4 primary care led projects.

The purpose of this newsletter is to provide more detailed information about individual projects. The project leads have been asked to respond to a number of questions posed.

## NHS Ayrshire & Arran

Caroline Hood (Project Lead)  
and Debbie Provan (Project Manager)

### *What are the problems your project is tackling?*

NHS Ayrshire and Arran's TCAT project is a 2-year project which began in November 2014. It aims to ensure person-centered care is central to the breast (year 1) and colorectal (year 2) cancer pathways, to empower and enable people to take an active role in their own health and well-being from diagnosis, and improve communication between care providers.

### *What new approaches/tools is your project using, how are you using them and what benefits are they providing?*

These aims are being delivered through 4 key pathway introductions:

- 1) A holistic needs assessment (HNA) at 3 time points in the breast cancer pathway (at diagnosis, end of active treatment and 6-8 weeks after active treatment).
- 2) A community Health and Well-being Clinic (H&WBC) (people with a diagnosis of breast or colorectal cancer are invited to attend 6 – 8 weeks after active treatment).

3) An End of Treatment Summary (EoTS)

4) A local authority-led rehabilitation programme, providing an opportunity for patients to exercise in a safe, local environment, engage in an education programme about healthy eating and access support to achieve and maintain a healthy weight.

These changes coincide with a change to the local breast cancer follow-up model which saw a move from clinic-led follow-up to a risk stratified model, which includes the option for patient-led follow-up with rapid access back in to secondary care if required.

### *What stage is your project at?*

To date, more than 250 HNAs have been carried out, 74 appointments have been made for the H&WBC and 13 fitness instructors have been trained to Level 4 in Cancer Rehabilitation.

What has been the biggest challenge and how have you resolved this challenge?

The introduction of the EoTS has been challenging since there is no national IT solution, and no dedicated administrative resource to pull together the information required. However the colorectal clinical nurse specialists are using the national



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template and beginning to introduce this into clinical practice. Other solutions are also being investigated in order to move forward within breast cancer services.

Only a small number of people have chosen to access the local authority-led rehabilitation programme. This is surprising given the fact the top 2 information needs of those diagnosed with breast cancer in NHS Ayrshire and Arran is 'Exercise and Activity', and 'Diet and Nutrition'. In order to improve uptake and promote the service, the Patient and Carer Panel are working with the Project Lead and Rehabilitation sub-group to develop a promotional leaflet which also enables individuals to self-refer to the programme.

### ***What has changed for the better with a result of the project for people with cancer and their families?***

The Patient and Carer Panel are considered a great asset, as information from this source has enabled the project team to relay important messages in an effective and supportive manner. The panel also provide support to Ayrshire and Arran's Phase 2 TCAT project, which means they have a good understanding of what is going on locally and help to ensure a cohesive and effective approach across both projects. The panel and Project Lead have also co-produced a leaflet which explains the purpose of the Health and Well-being Clinic.

Another success to-date has been the creation of a Supportive Care Directory. This tool supports the delivery of the H&WBCs, and the care planning element of the HNA. The directory has been made available to all NHS Ayrshire and Arran staff via our intranet, and it has been shared with the regional network. Its list of support groups and services are also being added to the forthcoming NHS Inform/ALISS directory, which will enable local people to identify and access services directly.



Steering group (clockwise from top left): Amy Kerr, Debbie Provan, Kevin Campbell, Caroline Hood, Nicola Holden, Margaret Welsh, Hazel Steel, Debby Wason, Nicky Batty and Karen Bell.

Project team (left to right): Nicola Holden (Administrator), Kirsty Gillespie (Health and Well-being Practitioner), Debbie Provan (Project Manager)



Our project is being evaluated nationally and locally. To date, a large amount of data has been collected however a thorough analysis has not been completed, and being at an early stage it is too soon to report on the impact of the service changes. Despite this, verbal feedback from those attending the Health and Well-being Clinic indicates that it is a welcome change and valued by attendees.

### **Next Steps**

Within the coming months the project team will focus on communication; aiming to improve awareness of the project, promote the rehabilitation classes, ensure people understand the purpose of the H&WBCs and increase the number of EoTS's being carried out. Data analysis will also begin.

### **NHS Borders**

**Judith Smith (Project Lead)  
and Alison Smail (Project Manager)**

### ***What are the problems your project has attempted to tackle?***

This was a Locality Based Health and Well-being Support Programme for people with Cancer in Hawick, with 61 patients and was completed in July 2015.

The overall aim of the project was to enhance patients' health and Well-being, by providing integrated support which is relevant to individual needs, promoted independence and healthy lifestyles.

We wanted to ensure people who have completed treatment for cancer are supported and prepared to live as independent a life as possible, and with confidence of knowing who to contact and when.

**What new approaches did your project use, how did you use them and what benefits are they providing?**

HNA – to complete at 2 key points in the pathway – 1 after diagnosis (if applicable during project) and 2 after treatment completed – copy to patient and GP along with an agreed care plan.

**Health and Well-being Events** - These comprised of information sessions / presentations and market stalls promoting local services.

**A Directory of Services** for TD9 area was developed. This was very useful for staff to signpost to services either at HNA or at the Health and Well-being event. We plan to expand this to cover the whole Borders region.

**Development of a TCAT Web page** informing patients of the pilot and hosting our online directory and a calendar of events. Staff were also signposted to this for information.

**A monthly newsletter** for information, which was distributed to NHS and Scottish Borders Council as well as handed to patients at health and well being events.

**1:1 interviews** with patients who had been through all aspects of our pilot to understand how successful it has been. The results will instruct recommendations in the evaluation. Patients don't seem to mind who completes the HNA or even remember completing it. Many concerns are coming up at the 1:1 interviews, possibly due to the interviews being some time after completing treatment or perhaps the HNAs were too soon, and they have had time to reflect on any learnings at the Health and Well-being event.

Developing an end of treatment summary for initial trial on patients finishing chemotherapy in the BMC. This is a big piece of work and was not possible during the project lifespan; however there is a drive to achieve this.

**What has been the biggest challenge and how have you resolved this?**

Small numbers of patients, however the outcomes are supportive of previous work carried out by NCIS in relation to the recovery package.

Many cancer patients in the Borders are diagnosed and treated in the specialist tertiary cancer centre in Edinburgh. A big challenge for the project was how we are informed of these patients to ensure all patients receive the same input. Utilised previously formed and developed new relationships with colleagues in Edinburgh. This has also highlighted pathways that need improving, which will be taken forward in the future.

**HNA** – Time to train staff in use of HNA and also support the roll out of it to increase confidence.

**Health and Well-being Events** – low number of attendees from pilot area. Addressed this by opening out to all Borders patients who had completed treatment.

**Directory of Services** – no integrated IT system made it a huge piece of work and there were a number of individual ones from different departments as well as social care and ALISS, therefore there was not 1 local directory that covered health, social care and community groups. We have now linked our calendar and directory onto our web page so anyone can access this. It was important to have this both on paper and electronically.

**Webpage** – as above.

**Newsletter** – could have circulated much wider if integrated systems in place.

**1:1 interviews** – time consuming and many issues raised by patients here that need addressed. This is something that needs taken forward.

**End of Treatment Summaries** – complex, lots of cancers, need to develop IT system, agree content, logistically challenging to complete consistently across the various cancer groups, clinicians and hospitals. Progress this by piloting an EOTS for all patients completing chemotherapy at the Borders Macmillan Centre.

**What has changed for the better with a result of the project for people with cancer and their families?**

- Improved patient centered care through use of these tools
- Empowering patients to make informed decisions about how to meet their needs
- Ensure everyone affected by cancer knows who to contact for what, and what their next steps are
- Improved confidence
- Peer support
- Improved partnership working from professionals resulted in smoother more linked up pathways

**Commentary from service users**

“Getting to speak to other people with the same thing was really helpful”

“I know where to look for something now”

“It's reassuring to know what's there, even if I never use it”

## NHS Lothian

Alan McNeill and Gillian Knowles (Project Leads), Mark Allardice (Project Manager)

### What are the problems your project is tackling?

NHS Lothian was awarded Phase I TCAT funding to pilot a recovery based approach to patients following treatment for cancer in a range of tumour groups. The project commenced in October 2014.

### What new approaches/new tools is your project using, how are you using them and what benefits are they providing?

An end-of-treatment recovery within the Edinburgh Cancer out-patient department for patients following treatment for anal cancer, cervical and endometrial cancer, breast and lung cancer. It involves a Holistic Needs Assessment and a supported self-management plan based round the key concerns identified by the patients at that time (approx 12 weeks and 6 months post treatment). The clinics are run by the site-specific clinical nurse specialist and the nurse consultant

An end-of-treatment recovery clinic for men following surgery for prostate cancer with a focused supported self management programme for urinary incontinence and erectile dysfunction, two symptoms that have been identified previously as a priority by patients within NHS Lothian. This clinic is multi-professional and includes a consultant urological surgeon, clinical nurse specialist and specialist physiotherapist.

### What stage is your project at?

We are currently 10 months in to a 22 month project. It was previously estimated that 60 post-prostatectomy patients would be offered this input over a six-month period and a minimum of 20 patients from each of the other cancer areas. Currently we have recruited 73 prostate and a total of 58 for all other tumour groups.

### What has been the biggest challenge and how have you resolved this challenge?

Key challenges have included:

- delay in project manager recruitment
- delay in recruitment in some of the tumour groups due to clinical constraints and unforeseeable sickness etc.
- higher than expected volume of non-consenters some initial Admin Issues (now resolved)

Despite the above challenges the clinical teams have progressed the recovery clinics as per the original time frame. We hope to complete recruitment by the end of Nov 2015 and while we may not reach the estimated recruitment target of 140 we anticipate being close to 120.

### What do you think/What has changed for the better with a result of the project for people with cancer and their families?

The Lothian project commenced prior to the National Project evaluation team being appointed and has therefore developed its own evaluation approach which includes the use of HNA and patient focus groups. It is too early for data analysis however from the rapid feedback evaluation the clinics are being reported very positively. For example:

*P36 "it was good to be able to speak about my feelings, worries, anxieties I had over the last 7 months. We discussed coping strategies and options for the future. I think the most important aspect for me was having a designated liaison nurse who I could contact to discuss my concerns. I found this so helpful, and still do, as you don't feel so alone"*

*P28 "I felt chatting with her was very helpful after treatment, and she helped me sort out any worries I had".*

### Next Steps

Over the forthcoming months we will continue to run the recovery clinics; patient focus groups are scheduled in Sept and Oct; and we will complete an evaluation of the project with a final report by July 2016.

### Key Programme Contacts

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### WoSCAN

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### TCAT Website

[www.scotland.gov.uk/Topics/Health/Services/Cancer/TCAT](http://www.scotland.gov.uk/Topics/Health/Services/Cancer/TCAT)



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