Macmillan Renfrewshire Transforming Care after Treatment ('TCAT') Project

EVALUATION REPORT

May 2018

Contents List

Acknowledgements

We would like to thank various people for their contribution to the Macmillan Renfrewshire TCAT project:

- TCAT Steering Group;
- TCAT Operational Group;
- TCAT Patient User Involvement Group;
- Lucy Johnston, Research Fellow, Edinburgh Napier University for evaluation of our data;
- Dr Natalie Rooney and Fiona Sinclair, Beatson West of Scotland Cancer Centre;
- Gleniffer Outreach for providing the venue and warm welcome;
- Lauren Barbour for kindly taking and donating photograph for the TCAT leaflets and posters; Jackie Henderson and Janice Harrison for being the models;
- Move More/Rays of Hope and all other Third-party organisations who linked in with TCAT.

We would also like to thank NHS Ayrshire & Arran and Stobhill Hospital for enabling a visit their offices to observe their HNA processes in practice.

Finally, we would like to express our very great appreciation to Macmillan Cancer Support for the project funding, the Royal Alexandra Hospital ('RAH') patients who participated in the project and the RAH CNSs (Breast/Lung/Colorectal), without whose involvement this project would not have been possible.

The statistics in this report are the results of a self-evaluation carried out by local project staff with support from Edinburgh Napier University TCAT Evaluation Team. The views expressed in this report do not necessarily represent those of Edinburgh Napier University or Macmillan Cancer Support.

Section 1 Executive summary

Background and Aims

It has been recognised for many years that despite excellent clinical care and support at diagnosis and treatment for cancer, patients often feel cut adrift at the point when their treatment finishes, and they are expected to return to a 'normal life'. However, this is often when their emotional, physical and financial difficulties come to the fore.

The aspiration for the two-year funding was that the Macmillan Renfrewshire Transforming Care After Treatment (Pilot) would further progress and extend the work undertaken within the Macmillan palliative care project and link into the established Macmillan Renfrewshire Libraries project. The TCAT pilot was an opportunity to link together pieces of work and learning and develop a pathway for patients to follow at end of treatment. We were aiming for a seamless transition from a medical model of care and treatment into the community for support and rehabilitation. The project aimed to develop and test a discharge pathway for patients after completing treatment for cancer that would facilitate a holistic needs assessment and support plan which would link the patient into community services.

The main aims were:

- To bring together the initial work completed in Renfrewshire by the Macmillan palliative care team, provision of a road map of community services;
- Seamless transition from a medical model of care and treatment into the community for support and rehabilitation to improve the emotional, physical and mental wellbeing of the patient;
- Longer term, for people recovering after treatment for cancer to feel more in control of their life and more confident about returning to their new normal.

Description of TCAT Project

At the expression of interest stage, we approached all cancer specialties hosted within the Royal Alexander Hospital (RAH) and offered them the opportunity to be involved with the pilot. The Breast and Lung team accepted our invitation and worked with us throughout the pilot. The learning and pathway was extended to patients at the end of their treatment for Colorectal in April 2017.

A patient focus group was established with representatives playing an integral part within the TCAT steering group. The focus group provided insight and feedback into all patient facing materials developed and assisted with the training needs for the staff within the pilot.

The pilot was run in three phases:

- The first phase targeted people to complete a pre-TCAT Questionnaire, followed by invitation to attend an HNA interview by trained Macmillan staff. The first phase also involved the production and circulation of posters and leaflets to the Royal Alexandra Hospital (RAH) and Renfrewshire GP surgeries to advertise the project and raise awareness of the work.
- The second phase implemented the HNA process and tested the pathway, and collated people's experience with TCAT process.
- The final phase of the project was to evaluate the project. This was supported by data analysis provided by Edinburgh Napier University (ENU).

Results:

Our Baseline pre TCAT questionnaire was returned by 62 patients. The survey highlighted that people's concerns were in the areas of communication, follow-up, information and support. For example, the lack of information available about treatment, side effects or local services were highlighted. There was also the view that the supports for patients at the end of their treatment were inconsistent across GP surgeries.

85 people attended a Holistic Needs Assessment (HNA) interview at Gleniffer Outreach. The average consultation took over 1hr. The majority of concerns identified resulted in sign posting or referral to services within the community as they were of a social rather than clinical nature.

The uptake from Lung and Colorectal patients was low; therefore, the majority of referrals to the TCAT project were for breast cancer patients. The outcome of the HNA meeting was a support care plan which was issued to the patient post meeting together with a summary of discussion and agreed actions. The individual's GP and Clinical Nurse Specialist (CNS) also received a copy of the documentation.

More than half of the participants (47) completed a Post Evaluation Questionnaire and the results received were positive.

- 81% responded that there needs were met completely in respect of knowing where to seek help if they needed it,
- 93% rated the support they received as very good or good and
- 75% said they could now manage their emotional concerns.

In addition local service professionals provided positive feedback on the benefits of Macmillan Renfrewshire TCAT. Further feedback is available in the report; however here are some examples from patients and professionals:-

"I valued the treatment and feedback I received at the clinic it was easy to understand what was being done and why." - Patient
"We thank Macmillan Renfrewshire and the TCAT project for inviting us to participate in this project with them and for keeping the project on track. To date our observation is that most patients find this beneficial so we are keen to continue." - Breast Care Nurse Specialist, RAH

The TCAT project collaborated with local council, charitable and non-charitable third sector services throughout the two year project. This not only worked well in bringing training courses to the Renfrewshire area, but also promoted all services. This work highlighted the benefit of integrating services across the spectrum of health, social and third sector organisation to the individual patients.

The TCAT project also introduced an End of Treatment Summary Form and worked with the Breast Care CNS to re-establish an End of Treatment Clinic that had been suspended two years previously due to lack of Breast CNSs at that time.

The results of the evaluation encouragingly highlight that people's confidence after treatment, support after treatment, knowing where to seek help if needed and understanding who to ask for help as well as managing their physical condition all scored much higher post TCAT.

Moreover, it emphasises the importance of continued collaboration between Renfrewshire HSCP, NHS and Third Sector Agencies to ensure the concerns of the people of Renfrewshire continue to be addressed appropriately.

Recommendations:

- Use the learning from the development of the TCAT pathway to inform the development of the role of the Renfrewshire community connectors and other pathway opportunities in the future, ensuring that the links established within acute services are continued. This will allow extension to other cancer types and to include those with long term conditions.

- End of Treatment Clinics to be continued by RAH Breast CNSs; this was found to be a necessary first step in supporting patients at end of treatment. Allow for sharing of information and side effects with the patient and their GP, and development of a consistent end of treatment approach within Primary care.

- Continue to work with partners to build community capacity and to provide an effective network to develop relationships and opportunities for joint working and training within Renfrewshire.

- Consider the use of technology to allow care plans and support information to be shared easily but within the legal framework of data protection.

Section 2	TCAT Renfrewshire aims and expected outcomes and project description

The Renfrewshire Transforming Care After Treatment ('TCAT') Project is a 2 year local project funded by Macmillan Cancer support through the TCAT programme. The TCAT programme is a partnership between the Scottish Government, Macmillan Cancer Support and NHS Scotland.

Renfrewshire is a diverse area of towns, villages and countryside covering 270 square kilometres and situated 7 miles west of Glasgow City.

Just over 174,000 people live in Renfrewshire. Over the next 20 years, the number of people aged 16-64 living in Renfrewshire is likely to fall and the number of children will remain broadly the same. A major change will be that the number of older people (over 65) will rise by 51%. Approximately 4,872 (2.8%) of Renfrewshire residents are members of an ethnic minority group.

In many ways Renfrewshire is similar to the Scottish average; however within this reasonably small geographical area there are extremes of affluence and deprivation. Taking the death rate for cancer in <75's as an example, in an area of deprivation (Ferguslie Park) this is 85% above the Scottish average, whereas an area of affluence (Ralston) is 23% below.

A key issue identified within Renfrewshire is variable practitioner knowledge of the wide array of services available in the community that are able to meet the patient's specific need. Patients involved in a local research project highlighted the need for a structured rehabilitation pathway post discharge to allow them to progress to what they viewed as normal living. The project aimed to develop and test a streamlined pathway for people at the end of treatment. Patients reported through various projects locally that at the end of treatment abandonment and loss of confidence, coupled with fear of recurrence, are predominant. A further aim was to improve support for patients at the end of their Breast or Lung cancer treatments by empowering them to not only cope better but also to live well beyond their treatment with cancer. It was also intended that once we had piloted and successfully tested the sustainability of the project within those two areas the project would be expanded to include other cancer types.

The objectives of the pilot were:

- To bring together the initial work completed in Renfrewshire by the Macmillan palliative care team, provision of a road map of community services.
- Seamless transition from a medical model of care and treatment into the community for support and rehabilitation to improve the emotional, physical and mental wellbeing of the patient.
- The long term goal of the pilot is that people recovering after treatment for cancer feel more in control of their life and are confident about returning to a new normal.

The expected outputs (i.e. the things that we wanted to measure or see as a result of the project were as follows:-

- Pathway developed for TCAT to receive referrals from Clinical Nurse Specialists;
- TCAT process operating effectively in Gleniffer outreach. Gleniffer outreach is a

service provide by Accord Hospice to support people in Renfrewshire living with life limiting conditions;
- Initial development and testing with Breast CNS of an end of treatment clinic and producing of an end of treatment summary;
- Holistic Needs Assessments and support plans completed;
- Evidence that cancer support after treatment could be provided by local community resources;
- Testing of Electronic Concerns Checklist Resource within the project
- Formation of a patient-led support group;
- TCAT process operating effectively in four participating libraries;
- Recruitment of volunteers.

Project Resources

The project funding allowed for the recruitment of two 0.5 whole time equivalent (wte) posts for the duration of the 2 year project and one 0.5 wte post for 12 months:

ROLE	HOURS	GRADE
Project Manager	18.75 > 27.65	J
Support Plan Coordinator	18.75	5
Communications and Media Assistant	18.75	4

Due to the support provided by Macmillan's Marketing Department there was no longer a specific requirement for a Communications and Media Assistant. The Project Manager's hours were increased to 27.65 hrs from October 2016, for the duration of the project.

The project sustained a loss of resource due to maternity leave at the end of year one and a long term sickness absence towards the end of year 2. This impacted on the volume of referrals that we were able to assess and ultimately being able to fully test and embed the pathway within the community.

The project was supported by a TCAT Steering Group, TCAT Operational Group and Patient User Involvement Group all of whom met on a regular basis to discuss the project's progress and agree next steps. Normal project governance was implemented throughout the duration of the project including reporting through Renfrewshire Joint planning and performance Palliative care group and the TCAT Steering group.

The project was progressed within three broad phases; development, implementation and evaluation.

The steering group with key stakeholders including representation from the patient user group was established.

The Patient User Involvement group was established during this phase with input from the TCAT User Involvement Manager. The group had involvement within the project Steering Group and contributed significantly to the development and evaluation of the project and in particular to the development of the local TCAT materials.

We commenced discussion regarding achieving one of the aims of linking two Macmillan funded projects together, TCAT and the library project. The libraries at this point had recently become substantively provided within Renfrewshire Leisure and a different volunteer led approach was being developed within the service.

This was in essence different from the previous Macmillan Library project led by the Community Palliative Care CNS as initially there was registered nursing staff leading the service. The learning from this made placing TCAT within the library difficult.

The original vision was that volunteers would be able to facilitate the Holistic Needs Assessment (HNA). After consultation with the Macmillan Cancer Information and Support Service based within Renfrewshire Leisure a decision was made not to pursue this as an option. At the same time Macmillan also advised, after an internal review, that volunteers completing the support plan aspects of the HNA was too much of a responsibility for a volunteer. An administration of an HNA and Care Plan requires skilled facilitation therefore robust governance, training and supervision would need to be in place to ensure that the volunteers were supported by all partners. This would need to be part of a wider issue and therefore not be possible within the time frame of the project.

The TCAT project then researched other suitable venues to conduct the holistic needs assessments in Renfrewshire, e.g. Advice Works premises, Lagoon Leisure Centre, local Supermarkets and Renfrewshire Carers Centre. The project chose Gleniffer Outreach due to its proximity to RAH and the availability of a quiet space.

The referral form and pathway was developed in partnership with the Clinical Nurse Specialists and discussed and approved at the steering group. On receipt of the referral the TCAT project would contact the patient and an appointment offered for a holistic needs assessment.

Those patients who agreed to a HNA were invited by the Project to complete the Macmillan Concerns Checklist in advance of their appointment. They were also asked to record their levels of concerns from 1-10. This helped as a guide about what was important to them. This enabled the Support Plan coordinator to discuss and prioritise the concerns and signpost or refer them on to the most appropriate source of information and support.

The HNA was facilitated by the project's Macmillan trained staff, the support plan coordinator and project manager, and the output was a Support Plan developed in conjunction with the patient. This was issued post 1-1 interview outlining a summary of the key points discussed and agreed actions (see Appendix 6). Copies of the Support Plan were also shared with consent with the person's CNS and GP. This enabled the health professionals to be kept updated on their patient's ongoing or new concerns and the actions recommended.

The patient was supplied with contact information if another appointment to discuss the support plan was needed, a return appointment was not routinely offered. This was due to the significant time required for each appointment, highlighting the need for further training and support for the support plan coordinator to enable them to focus the conversation.

To support the service development and delivery the TCAT project team attended the following Macmillan Cancer Support training courses:-

- Communication Skills
- Dealing with Loss, Grief and Bereavement
- Emotional Wellbeing

- Managing Volunteers
- Motivational Interviewing
- Sage and Thyme
- Understanding Cancer and its Treatment

Project Evaluation

Approximately two months following HNA appointment a post TCAT Questionnaire was issued; the aim of which was to gather information on how confident people felt after participating in TCAT.

Following HNA appointments, the TCAT project input unidentifiable patient data into the various ENU databases from June 2016 – 15 December 2017. This enabled Edinburgh Napier University to collate the local data and provide reports on the information received to allow the project to draw conclusions.

In January 2018 ENU also carried out a triadic interview process with patients where they:-

- Interviewed patients about the TCAT service;
- Interviewed the Support Plan Coordinator about the patient and
- Reviewed the Care Plans.

47 patients were invited to interview with 8 people agreeing to participate.

As part of the evaluation process the TCAT project invited feedback from professionals and services regarding the impact that TCAT made to them and their patients.

Local Collaboration

Achieving TCATs aims required the team to build, explore and network with already established and new community services. It utilised work completed by the Renfrewshire Palliative care project with every patient assessed being issued with “about me, about my care” pack. TCAT engaged and collaborated within many services that were seen as necessary to provide the services required by patients post treatment to address their needs. The project worked closely and developed pathways to Move More, the Fear of Recurrence project in the Beatson, community link workers and multiple third sector agencies offering complementary therapies.

Section 3 Baseline Information Pre TCAT Project

During the development phase of the project, the RAH Breast and Lung CNSs invited patients who had completed their treatment during the previous 12 months to complete a pre-TCAT Questionnaire (see Appendix 1). This enabled the project to identify themes that would assist with the project and also provide baseline information for the evaluation.

The project received 62 questionnaires a 58% response rate, from patients which gave baseline information on the experience of patients regarding their confidence at the end of treatment prior to the TCAT project starting.

The majority of questionnaires returned were from females (90%) and the remaining 10% from males. The largest group was breast cancer (77.4%).

From the 62 returned questionnaires four themes emerged which assisted us to focus of the TCAT project's work:

Theme 1: Communication

Improved communication with GPs via direct contact to find out how their patients were feeling post treatment was highlighted as a concern with different approaches from GP practice to GP practice. Having a consistent approach adopted throughout Renfrewshire GP surgeries post cancer treatment would be beneficial.

The timing of the contact after treatment was considered crucial, but there were differing opinions with some people recommending a phone call after 12 weeks while others suggesting that they would have benefitted from having a chat six months after finishing treatment. Importantly, there was emphasis on the need to have a person at the end of the telephone rather than an answering machine.

Theme 2: Follow-up

The opportunity to discuss concerns with a CNS after each hospital appointment was requested as routine. Due to these ongoing concerns patients recommended that there should be faster response times to report mammogram results and to make quicker follow-up appointments. It was also considered useful to speak to someone earlier in their treatment journey.

Theme 3: Information

People also asked that the Clinical Oncologist give patients more information on how successful their treatment has been and also more information on the side effects of medication. They explained that a lot of time was wasted trying to find information on their own but the positive side of that is that some realised there is more support available than they knew about. More information regarding grants and benefits available and more information on workshops, e.g. Breast Cancer Care Moving Forward course, Gleniffer Outreach Fatigue Management class was requested. Many people highlighted the fact that information on local support was required and perhaps even an online link or drop-in service could be provided.

Theme 4: Support

Some people commented that they had to be proactive and find support. Providing a service to attend courses after working hours was also requested.

Section 4 Activity analysis

Referrals into TCAT

The project began testing the pathway on 27th June 2016. The project originally identified that they had the capacity to complete 320 referrals during its duration. However, due to project resource challenges, maternity leave and long term illness, this figure was not able to be achieved.

From the 107 referrals received, 85 patients accepted the invitation to attend for a HNA, an uptake of 79%.

The reasons for the difference between referrals received and those attending an HNA were:-

- Failure to attend appointment;
- Feeling that they did not require the service;
- Returning to work;
- Referrals for patients who lived out-with the Renfrewshire area so not within the projects remit.

The majority of referrals seen came from the RAH Breast CNSs. Lung and Colorectal DNS also referred into TCAT but uptake by these patients was very low. We have discussed possible reasons for this.

The project also received a few self referrals from people outwith the project criteria and it was useful to test if the same process and tools could be utilised to assist them, which also proved successful.

Cancer types

Data was unavailable for 1 participant, therefore data is presented for the following 84 participants with the data available:

Cancer	Number	Percentage
Breast	75	89.29%
Colorectal	3	3.57%
Lung	3	3.57%
Other (Prostate/Spine/Tongue)	3	3.57%
TOTAL	**84**	**100%**

There was no distinction made in relation to protected characteristics . Everyone within the project's criteria of 'End of Treatment' for Breast and Lung cancer patients was offered the opportunity to attend a HNA.

The demographic data below represents the 85 patients who provided data and input into the ENU CORE and PROCESS databases. The average age of the participants was 58. Due to the project being linked with Breast Cancer the majority of people attending the service were ladies with Breast Cancer.

Gender

Gender	Number	Percentage
Male	7	8.24%
Female	78	91.76%
Total	**85**	**100%**

The types of cancer diagnosis and treatments varied from person to person. Some received surgery or chemotherapy or radiation, and some a combination of only one or two treatments.

Ethnicity

The majority of participants within the project described themselves as White Scottish. One person was Asian and one European. An interpreter was provided from NHS Glasgow to assist with communication.

Economic Activity

Data was unavailable for 3 participants, therefore data is presented for the 82 participants with data available:-

Economic activity	Number	Percentage
Employed	39	49%
Unemployed	3	3%
Retired	36	45%
Looking after Home and family	1	1.22%
Long term sick or disabled	3	3.66%
Total	**82**	**100%**

There was almost a 50-50 split between those people employed and in retirement.

ECOG Performance Status

All but one of the participants scored between 0 and 2 within the performance status, indicating that they were between fully active with no restriction to being ambulatory and unable to carry out any work activities.

Concerns reported by patients after Treatment

80 participants had HNA concern checklist data available and this is presented below. The total number of concerns reported was 730. The average number of concerns per individual reported was 9 from the 57 concerns listed. The average overall priority level per concern selected was scored really highly at 8.

Domain	Number	Percentage
Physical	379	52%
Emotional	139	19%
Practical	91	12%

Lifestyle or Information	85	12%
Family and Relationship	25	5%
Spiritual or religious	11	1%
TOTAL	**730**	**100%**

More than half of the concerns were physically related. This can be a consequence of cancer treatment, and/or the fact that many patients do not return to full health and have to learn to live and manage long term side effects. The next highly identified group of concerns were around emotional issues such as anxiety, worry and feeling low. The practical concerns related to a diverse range of issues which included housing issues, personal care and finance. Lifestyle or information covered exercise, sleep patterns and disturbances, eating more healthily and worries about whether the cancer would return. The family and relationship concerns in the main were around how their spouses and children were coping and unfortunately there were not many services available for young children to discuss their fears. A minority of people had spiritual or religious concerns.

The care plan developed to support the management of these concerns was appropriately sourced from services within the local community as opposed to requiring the ongoing input of the clinical team.

The top 10 concerns are shown below:

Concern	Frequency
Tired/exhausted or fatigued	47
Sleep problems/ nightmares	38
Hot Flushes	38
Worry, fear or anxiety	36
Pain	33
Exercise and activity	27
Tingling in hands/feet	23
Loss of interest/ activities	21
Getting around, Sadness or depression	20
Memory or concentration	20

Support provided by TCAT

Following the HNA assessment the Macmillan Renfrewshire TCAT Support Plan coordinators signposted and referred people to various community organisations. Macmillan Renfrewshire TCAT were key to helping the Macmillan Renfrewshire 'Move More' project get started by inviting everyone who expressed an interest or identified exercise as a concern to consider a referral to Macmillan Move More Project.

Data provided by ENU showed that 66 of the 85 participants were formally referred to one or more support agency following completion of their HNA. In total 36% of referrals were made to other local authority services, such as leisure services with 28% of referrals being to a voluntary organisation.

The following table highlights the other services people were referred to though this figure is not entirely accurate due to the finite number of referrals (e.g. 4) you could add on the ENU database. For example, many individuals who presented were referred to more than 4 agencies.

Formal Referral	Number	Percentage
NHS specialist cancer service	7	4%
Their own GP	1	0%
NHS general	9	9%
Other local authority services	39	36%
Specialist benefits/ financial advice agencies	6	3%
Vocational support/ back to work	1	2%
Your local TCAT projects health and wellbeing events	0	0%
Cancer specific third sector	35	28%
Other	14	
TOTAL	112	100%

One in five (21%) discussed returning to work as a concern and they were signposted to either Renfrewshire Council's Disability Employment Advisor, Beatson's Specialist Health and Work Practitioner or to Macmillan Cancer Support's Employment Service. In the main this was due to people needing to know more about their rights as an employee post cancer treatment and how they are protected by law from unfair treatment at work.

Was the patient signposted to any other sources of advice/ support?
Data was missing for 5 participants therefore data is presented below for the 80 participants with data available:

Answer	Number	Percentage
Yes	78	97.5%
No	2	2.5%
TOTAL	80	100%

If yes, please tell us where the patient was signposted to?

Signposting	Number
NHS specialist cancer service	19
Their own GP	41
NHS general	5
Local authority Social care/ Social work	2
Other local authority service e.g. housing or leisure	35
Specialist benefits/ financial advice agencies	4

Vocational support/ back to work specific agencies	9
Your local TCAT projects health and wellbeing events/ activities	0
Cancer specific third sector	69
Non cancer related third sector/ organisation	33
Other	12

Finance was a problem for some however in this cohort we found that this had been identified at the beginning of treatment with Renfrewshire Council's Advice Works being involved with assisting patients with advice and completing a Personal Independence Payment application. The TCAT project also identified some ongoing concerns and referred a small number of people (3%) to Advice Works.

Since it was clear from the top 10 concerns that fatigue was a major issue for patients which meant their ability to travel to Glasgow for services was reduced, the TCAT project contacted Dr Natalie Rooney, Psychologist, Beatson to ask if she could bring her Memory & Concentration and Fear of Reoccurrence Courses to Renfrewshire. This proved a great success. As a result of that collaboration, Gleniffer Outreach benefited too. More information on this is provided in Section 11 'Other Service Activity'.

Dependent upon the nature of the patient's concerns, the Macmillan Renfrewshire TCAT project resource did their utmost to assist where appropriate to do so. However, the administration time, post HNA interview, in helping to resolve people's concerns was very time consuming and this should be factored in when considering how the service will be managed post TCAT.

Section 5 Participant Feedback

Approximately 6-8 weeks after HNA, Post TCAT Questionnaires were issued to patients, 47 of the 85 were returned.

In the Post-TCAT Questionnaire patients were asked to evaluate the service on a scale from 1-10. With 1 being 'Not at all Confident' and 10 being 'Very Confident'. The TCAT project has based the percentages below on the response levels given by patients from 7-10 as they feel that people scoring a 7, 8 and 9 will still have some level of confidence.
The complete results can be found in Appendix 14.

SURVEY QUESTIONS	PRE-TCAT (62 Respondents)	POST-TCAT (47 Respondents)
Confidence after Treatment	54%	90%
Support After Treatment	75%	93%
Managing Side Effects/Consequences of Treatment	43%	55%
Knowing where to seek help if needed	61%	81%
Understanding who to ask for help	62%	81%
Awareness of support available to your family/carers	36%	52%
Knowing about other support services or groups you could use	36%	65%
I was passed around from person to person without getting the support I needed	18%	10%
I was assisted to get other services and help, and to put everything together	50%	93%
I have been involved in decisions about my care and regaining my wellbeing	60%	83%
I know where to seek help to manage my physical condition	66%	82%
To manage practical concerns such as shopping, housework and travel	71%	73%
To manage my financial concerns	73%	52%
Getting back to work	41%	34%
To manage family/relationship issues	65%	63%
To manage my lifestyle e.g. diet and level of physical activity	55%	69%
To manage my emotional concerns	38%	75%
To manage spiritual or religious concerns	61%	21%
Since your treatment has finished have you used/visited any organisations, services or individuals for information, advice or support?	70%	96%

Feedback was overwhelmingly positive as patients felt more confident generally in comparison with the baseline figures.

Patient Case Story

Most of the people receiving a HNA expressed satisfaction at the service offered although some have commented that they would have preferred to have received the intervention much earlier in their cancer journey. Here are examples of service user stories:-

"I was diagnosed with breast cancer in March 2015. I had chemotherapy and radiotherapy at the Beatson in Glasgow.
I had some side effects from the treatment that left me with temporary and some permanent mobility problems.

During my journey I found I did not know of support networks that were available to me. At one of the patient user groups for fitness, I was asked to be part of the TCAT service groups, to discuss my experiences after my treatment. On having a TCAT holistic assessment this then opened a wider door to me, ie… a dietician to discuss weight gain from my treatment. It then gave me the opportunity to attend a programme for "chemo brain" - cognitive memory, and allowed me to attend classes to improve my memory. I was invited to a course for Fear of Reoccurrence, the tools to manage pain and this allowed me to reduce my prescriptions for pain relief.

In my experience from the final treatment you feel abandoned and alone with no knowledge of who to turn to; should it be your GP or Breast Care Nurse. No information was given to me at the end of my treatment. TCAT provided me with the knowledge of what financial assistance could be offered to me with my treatment finishing. The only other information given at the start of my treatment was from the MacMillan Nurses. I, personally, for a time, was being paid by my employers. However, this is not the case for everyone.

TCAT is a valuable service and can create a whole new bright outlook for people, in that you do not need to be alone. The TCAT service was totally confidential, non-medical, hugely holistic, which after a year of treatment was utterly beneficial. The whole approach was centred on trust, encouragement and a listening ear and commitment when needed.

It would be a shame if this project was only to be a trial. Personally, I found it invaluable in progressing my ability to return to work and feel like a "normal" person, and less visits to my GP overall. I want to thank you for being part of the TCAT project. Without it I would not be the person I am today!!!"

- JH (Renfrewshire)

After my treatment concluded, I was a post cancer patient similar to a deer caught in headlights. There didn't seem to be anywhere to turn.

Attending meetings and having a HNA, I realised that help was there, if only you knew how to source it. I was signposted to various organisations to help

with finances and help with post chemo side effects. I attended a Moving Forward course, Fatigue Management and Coping with Memory issues.

I am now more confident to deal with issues. I am stronger and fitter due to various exercise classes and walking groups. I was given a great link to free Mindfulness Audio material which certainly helped me with mental health issues.

I had great support throughout my TCAT journey meeting very dedicated people along the way."

- HB (Renfrewshire)

"A good initiative which gave me the opportunity to discuss and explore areas that may have been causing concern and it was nice to have the reassurance that the response was professional, patient focused and could signpost me to services available within the Renfrewshire Council area, if necessary."

- AB (Renfrewshire)

Actual statements received from patients about TCAT

"Talking to other ladies who've been through a similar experience."

"1-1 Advice and Guidance Tailored to my Individual Needs."

"Ability to discuss concerns and knowing time for discussion was available."

"The lady put me at ease; she was lovely and very professional and seemed to know her job very well."

"The opportunity to speak to someone about issues and concerns."

"Very helpful nursing staff and after care."

"Just being able to chat about what was bothering me and being told things I had forgotten."

"The information given to me was valuable."

"The clear way in which things were explained."

"The understanding and empathy shown, help and advice, I didn't know what was available."

"Meeting up with other people, laughter with hair/wig consultant - excellent".

"The face to face aspect of it, made to feel at ease, not rushed."

"Home service very good."

"The information that was given to me about classes and support groups".

"Ensure staff and resources available to sustain the service as project becomes better known."

"Possibly offer TCAT to people who have had cancer in the past, when this service was not available".

Professional and Agency Feedback

Below are testimonials of the impact Macmillan Renfrewshire TCAT project had on a range of local -and Glasgow services as evidenced by the professionals involved:-

"We thank Macmillan and the TCAT project for inviting us to participate in this project with them and for keeping the project on track. To date our observation is that most patients find this beneficial so we are keen to continue."

- *Fiona Irvine, Breast Care Nurse Specialist, Royal Alexandra Hospital*

"The TCAT Project initially contacted me at the Beatson to enquire about the support services provided by the Clinical Psychology Department as part of the TCAT Cognitive Rehabilitation Project and the Breast Cancer 2000 Fear of Recurrence Project. At the time, the group programmes were being delivered in the Glasgow area and therefore limited access for those living out with the area. The TCAT Project raised the concern that the individuals accessing their service often present with post treatment fatigue and therefore may pose a barrier to attending the group programmes. As difficulties with memory and concentration and emotional distress were frequently reported through the Holistic Needs Assessments (HNAs), the TCAT Project enquired whether a bespoke group could be delivered for individuals living in the Renfrewshire area. As a result the 'memory group' was brought to the Royal Alexandra Hospital site which therefore increased access for individuals living within this catchment area. The TCAT Project was one of our key referrers and we remained in close communication with regards to the progress of the individuals on the group programme as well as with their on-going support needs.

Moreover, the individuals who had accessed a HNA with the TCAT project spoke highly of their contact with her and the service as a whole. I repeatedly heard feedback from individuals regarding the value they placed on receiving this person-centred support. I understand that the model of follow-up support which was initiated by the Renfrewshire TCAT project has been implemented by the Breast Clinical Nurse Specialists (CNSs) based at the RAH and we continue to receive referrals from the CNSs for the Fear of Recurrence project."

- *Dr Natalie Rooney, Macmillan Principal Clinical Psychologist, Beatson*

"The TCAT project has paved the way for cross sector working and provided the much needed link between the NHS and the Third Sector. I believe this is just the beginning and there is a cultural shift beginning that involves everyone recognising the value of working together with the patient at the centre of the care. We have made an excellent start, now let's take it to the next level."

- *Angela Harris, Head, Breast Cancer Care*

"Day 2 in Paisley – again, quieter than normal as a result of poor weather. Reached 45 people between bus and an outreach in Boots. Also had a successful health walk leaving from the bus with 12 participants. Great support again from Renfrewshire TCAT Project. Really tried to push local info and support services on the day."

- *Joyce Dunlop, Quality Lead, MacMillan Cancer Support*

"TCAT has played a fundamental part of initiation and development of Move more. Throughout

the project, TCAT have referred a significant number of people affected by cancer for support in becoming more active. In turn, this has been reflected in the increased self-efficacy, quality of life and health related outcomes that have been witnessed in Move More referrals. It is through this partnership working that has allowed knowledge has been exchanged between Move More, TCAT and health professionals - facilitating the growth of Move More. Thanks to TCAT, Move More now works closely with a variety of CNS's to ensure everyone affected by cancer is offered the opportunity of physical activity behavioural change support."

- *Ruth Miller, Renfrewshire Leisure Macmillan Move More Development Officer*

Working within the community it is imperative that we work closely with our partner agencies and I was grateful to the TCAT project for contacting us with information which we think helped to alleviate some of the lady's concerns."

- *Sgt Michael Hart, Ferguslie Park Police Office, Police Scotland*

"The Macmillan Information & Support Library service benefits greatly from partnership work and collaboration with other local services. Through signposting, referrals and linking in with projects like TCAT we are able to work together to provide a person centred approach to our service. This has been through a mix of ongoing contact and support as well as individual events such as Macmillan's Mobile Information Bus which have allowed us to expand and reach more people who are in need of our service."

- *Scott Logan, Macmillan Living Well Co-ordinator, Paisley Libraries*

"I do have a very positive experience after I attended a TCAT meeting some time ago in Dykebar Hospital in my role as a Community Link Worker.

The meeting really made me aware of the support available to cancer sufferers that they or their families may not be aware of.

We discussed how both services complement each other and this better informed me of the different types of interventions offered here. Also being able to say to service users that I know the staff at the service gives them more reassurance and, I think, a better chance of them engaging with the service.

- *Irene Brown, Community Link Worker, RAMH*

"Before the TCAT project started in Renfrewshire, Gleniffer Outreach had already identified there was a need for 'after treatment support' as we were regularly having people drop in suffering with anxieties and issues after completing their cancer treatment. There was a gap in the service.

It was great to have the TCAT project to channel these individuals towards and know that time would be taken to get to the root of their anxieties and that help would be sought.

Hosting the appointments was particularly helpful at breaking down any barriers an individuals may have faced coming to our building as a 'drop in' client.

We hope the results from the TCAT project indicate that there is a need for care after treatment and that this kind of work can continue and can be expanded across all cancer

patients not just breast or lung cancer patients.

- *Amy Crawford, Outreach Co-ordinator, Gleniffer Outreach*

"Well in Renfrewshire ('WiRe') is an online directory of local clubs and groups across Renfrewshire. Vital to its success is ongoing engagement with partners, clubs and groups, and the public.

The TCAT Patient User Involvement Group was one of the first groups to test WiRe. The feedback received played a key role in the development of WiRe, in terms of design, content and how we engage with potential users of WiRe. I'm pleased to report that the Group found WiRe very useful in accessing information about groups in their local community.

Engagement with staff and partners has also been important to WiRe's development and the TCAT team provided helpful feedback on how WiRe functions from the point of view of a worker supporting a service user.

I would hope that the TCAT team and the Patient User Involvement Group will continue to play a role in the development of WiRe."

- *Alan Mair, Snr Community Link Officer, Renfrewshire Council*

"Working with the TCAT team in Renfrewshire we have seen a considerable increase in the number of people accessing our complementary therapy service in the area. By working together we are able to boost awareness of both organisations and support people who may not have known about the services otherwise, which is fantastic. The team are always happy to help and we look forward to continuing this partnership."

- *Grant Aitchison, Community Outreach & Volunteer Co-ordinator, Cancer Support Scotland*

"*With Rays of Hope being a small part of the Third sector it was wonderful to be recognised by a project as TCAT and be involved with what they were doing"*

- *Linda O'Malley, Founder, Rays of Hope*

Section 6 Recommendations

With the NHS being as stretched as it currently is and with the increase in cancer survivors it is important that the holistic needs assessments continue along with collaboration within the local community services.

The results of the TCAT project have clearly highlighted the demand and benefits of continuing and supporting this service. The number of cancer survivors increase is estimated to double proportions by 2030. Therefore the NHS, Renfrewshire HSCP, Third sector organisations and other Community Planning Partners will be unable to cope with the huge increase in demand for services as it is already the case that they are stretched and in some areas in crisis.

Throughout the project it was made clear that there was no funding for continuing the TCAT post after the two-year project ended. As a result the future sustainable measure for consideration was the methodology could be continued within the current establishments within Renfrewshire HSCP, NHS and Third sector organisations and the following recommendations have been made:

- Use the learning from development of the TCAT pathway to inform the development and the role out of Renfrewshire community connectors and other pathway opportunities in the future, ensuring that the links established within acute services are continued. This will allow extension to other cancer types and to include those with long term conditions. Continue to test the methodology to confirm that male patients will also engage with the service as due to the limitation of the project the pathway was tested with female patients almost exclusively.

- End of Treatment Clinics to be continued by RAH Breast CNSs; this was found to be a necessary first step in supporting patients at end of treatment. Allow for sharing of information and side effects with the patient and their GP, and development of a consistent end of treatment approach within Primary care.

- Continue to work with partners to build community capacity and to provide an effective network to develop relationships and opportunities for joint working and training within Renfrewshire.

- Consider the use of technology to allow care plans and support information to be shared easily but within the legal framework of data protection.

Community Connectors

The role of Community Connectors is to support and strengthen the connections between GP practices and the third sector to enhance patient wellbeing. There are 8 RAMH community connectors linked in across Renfrewshire aligned to specific GP practices. The connectors can support patients to access and utilise services within their local communities which will help them address any underlying issues impacting on their health and wellbeing. By taking a person-centred approach it will enable individuals to be supported to identify and achieve positive outcomes. This approach

can help empower people to better manage their own wellbeing through combating isolation, providing motivations for lifestyle change, building confidence and support networks, linking to practice resources and help people navigate additional services. The community connector's aim to be self-sufficient and therefore, complement the work of the GP practice team. By providing this additional resource they are able to promote self-management and extend the reach of health interventions into the heart of the community. The service is locally based to ensure the full utilisation of existing community resources and also identify gaps in local provisions which can then inform future community led projects.

The TCAT project recommended utilising the community connectors' service to provide sustainability for the project going forward. The Renfrewshire Community Link Manager raised the topic with the Renfrewshire Strategy Director who also agreed with this suggestion.

The TCAT project successfully proved proof of concept within a short timeframe. Going forward to the end of the project in April 2018, it delivered the following:

- Demonstrated that patients following completion of treatment could be supported within community resources to improve their confidence in managing their concerns;
- Tested the service process with other cancer types;
- Monitored success or otherwise of End of Treatment Clinics;
- Facilitated ENU interviews with a small group of patients;
- Circulated TCAT local information directory to RAH CNSs and TCAT network;
- Provided relevant Data Links to NHS Inform and eCCR.

"I found TCAT invaluable in progressing my ability to return to work and feel like a 'normal' person, and less visits to my GP overall. I was also able to reduce my pain medication. I want to thank you for being part of the TCAT project. Without it I would not be the person I am today!" - *Patient*

Section 11 Appendices

No.	Topic	Document
1.	**Pre-TCAT Questionnaire**	Pre-TCAT Questionnaire.pdf
2.	**RAH CNS TCAT Referral Form**	TCAT Referral Form.pdf
3.	**TCAT Patient Invite Letter**	TCAT Patient Invite Letter.pdf
4.	**ENU Pre and Post TCAT Evaluation Papers**	ENU Pre-TCAT Questionnaire Report ENU Post-TCAT Questionnaire Report
5.	**Macmillan Concerns Checklist**	Sample TCAT Concerns Checklist.pd
6.	**Macmillan Care Plan**	Example Care Plan LC.pdf
7.	**Post TCAT Questionnaire**	Post TCAT Questionnaire.pdf
8.	**Patient Invitation to attend ENU Interview**	ENU Patient Evaluation Interview
9.	**Renfrewshire's Full Demographic Profile - Scotland Census 2011**	Scotland Census 2011 - Population by SC 2011 - Long term disability by sex and a Scotland Census 2011 - Age and Disab
10.	**Macmillan Renfrewshire TCAT Volunteer Report**	Renfrewshire TCAT Volunteer Model.pdf

11.	**TCAT Leaflet and Poster**	TCAT Refrewshire - Leaflet. pdf TCAT Renfrewshire - Poster.pdf
12.	**Macmillan Renfrewshire TCAT/Move More Referral Form**	Example of TCAT/ Move More Referral F
13.	**Directory of Local Community Organisations**	Directory of Local Community Organisat
14.	**Renfrewshire Map**	Renfrewshire Map (Post Codes) 260716.
15.	**End of Treatment Summary**	Sample End of Treatment Summary F
16.	**Word Care Plan**	Word Care Plan.pdf
17.	**Pre-TCAT/Post-TCAT Comparisons**	Pre-TCAT and Post-TCAT Comparisc