DEVELOPING A RECOVERY-BASED APPROACH TO CANCER CARE IN NHS LOTHIAN

MACMILLAN CANCER SUPPORT FUNDED PHASE I PILOT PROJECT

NOVEMBER 2014 – FEBRUARY 2016

Submitted by NHS Lothian TCAT Project Team: 25 August 2016
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Executive Summary

This paper reports on the evaluation of a recovery-based approach to cancer care. This project (funded by Macmillan Cancer Support Transforming Care after Treatment Programme) is in line with NHS Lothian’s clinical quality approach aiming at improving the delivery of a service that is responsive to patient need and support’s people’s choices. Adopting a more systematic approach to assessment has been found to minimise distress and enable people to become more involved in their care and more proactive in their recovery. This is in keeping with recent government publications that describe one fundamental question to underpin discussions with patients “what matters to you” (Scottish Government 2015; Scottish Government 2016).

This project implemented a Holistic Needs Assessment (HNA) at 6-12 weeks post treatment and again at 6 months for patients with breast, gynaecological, anal/rectal and lung cancer patients. An agreed care plan was then formulated where advice and interventions were aligned with problems identified by individuals. A summary was generated for community staff outlining the key concerns raised by the patient and any advice, intervention or referral that may have been suggested. A secondary objective was to evaluate the feasibility of embedding this service into everyday care and to assess whether there were common themes for all patients or within specific site-specific tumour types. Prior to starting, training sessions in the use and delivery of HNA’s were provided from the Psychology team.

Between November 2014 and October 2015 82 patients were invited to join the project and 61 (74%) agreed to participate.
- The median age of the participants was 58 years representing a significantly younger groups than the non-responders with a median age of 73 years
- A majority of those who participated were working (57.4%) and of those who declined, a higher percentage were retired (52.4%)
- There were a higher proportion of patients with lung cancer declining participation (41%) which may be related to higher co morbidities in this group. Any future interventions should consider this.

The Key finding from this project is:

We have demonstrated that with adequate infrastructure in place, this recovery approach is feasible and beneficial in the recovery of patients following treatment.

Overall findings
- The average number of concerns reported at TP 1 was 6.65 (range 1-22) which reduced significantly to 3.38 (range 1-20) by TP2 (p=0.00003). The greatest decreases were reported in lifestyle and practical issues
• The most common top three concerns at TP1 were listed as tiredness or fatigue, hot flushes and sweating and worry, fear or anxiety. At TP2 they included worry, fear or anxiety, tiredness or fatigue and sleep problems or nightmares.

• The most common interventions offered to participants in helping them manage their concerns were symptom assessment and advice along with assessment of emotional well-being being the most frequently reported followed by general exercise advice. Specific targeted advice was given to specific tumour groups which included the use of vaginal dilators in gynaecological and anal cancers and breathing techniques in lung cancer. Overall the issues of fatigue, worry or anxiety and sleeping problems were common to all tumour groups.

• Seven out of 61 (11.5%) were referred to psychology suggesting that some patients have major psychological concerns following treatment.

Patient reported benefits

• This approach offered supported transition to supported self care
• It enabled patients to take re-gain control and self manage concerns
• It gave participants the opportunity to discuss ongoing issues following treatment with an experienced, skilled and knowledgeable CNS/Nurse Consultant in that field
• There was valuable input from CNS/Nurse Consultant at difficult times when patients are feeling isolated

Staff reported benefits

• The provision of a framework to assess and understand about what matters to patients following treatment and what are the ongoing concerns
• It highlighted the necessity of rescue work required following treatment with the potential to reduce unscheduled hospital/GP appointments/admissions
• The project enhanced service integration through the building of relationships with the voluntary sector, community services and local authority

Feasibility

• The length of consultations and post clinic work was recorded and the average length of consultation was 70 minutes at TP1 and 66 minutes at TP2 resulting in an increase in workload of approximately 2 hours per patient.
• Infrastructure to support this project included team training in HNA’s, secretarial support and clinic space
• Whilst there was real benefit in the recovery approach further thought needs to be given to whether other time points in the pathway for HNA’s would be beneficial

Ongoing work

Based on the positive findings the project teams are looking at adapting this approach and embedding HNA’s in practice. Specific work includes:

• All patients with breast cancer on completion of chemotherapy and all patients treated with pelvic radiotherapy for anal cancer will be offered a one-to-one consultation, using a HNA to support them in their recovery. A telephone consultation will be offered to those who do not want to attend for a hospital visit.
• An educational event to highlight the benefits of HNA’s to CNS within the Cancer Centre
• A review of existing practices that support patients who experience late effects/consequences of pelvic treatment and to devise recovery referral pathways
• A review of existing clinical commitments and the feasibility of embedding recovery clinics within clinical sessions as part of job planning
• The project team will present the findings to the Edinburgh Cancer Centre’s Clinical Management Board for discussion around implementation and sustainability for all tumour groups
• Present findings to the SCAN TCAT Group and the TCAT Programme Board

Recommendation

Our recommendation is that this recovery approach is beneficial and should be considered for all tumour types with adequate infrastructure in place. However, this needs to be considered as part of NHS Lothian’s over cancer work plan.

Future Plans

• The project team will deliver educational sessions to ensure wider dissemination and facilitate discussion on the use and implementation of this approach within our services
• The project team will disseminate their findings through publication in nursing journals to ensure wide dissemination and shared learning across the UK
• The project team will continue to build and strengthen relationships across health and social care, local authority and the voluntary sector
and develop a NHS Lothian service directory of resources available to support people in their recovery from treatment.
Introduction

It is now widely recognised that the numbers of people who are living with cancer in the United Kingdom is increasing with an anticipated increase from 2 million to 4 million by 2030 (Maddams et al 2012). Based on these current trends, for Scotland this is an estimated increase from 190,000 in 2010 to approximately 340,000 by 2030.

While this is very encouraging, as survival increases there is a growing awareness of the need to understand the consequences of cancer treatment to support people in their recovery and optimise health-related quality of life (Richards et al 2011). There is also evidence to suggest that approximately one third of people surviving cancer have a range of unmet needs following treatment (Armes et al 2009). The impact of this can be significant and has the potential to hinder recovery and adaptation and may result in the need for increased health and social care services. With this comes a growing recognition of the need for health and social care professionals to help prepare people for the future and return to a lifestyle as near normal as possible. Therefore learning more about how people experience the consequences of cancer in their daily lives, in the context of their family, work and social environment is important. In doing so, there is the potential to maximise appropriate use of resource while supporting people to live as healthy lives as possible.

The Transforming Care After Treatment Programme (TCAT) is a five year programme funded by Macmillan Cancer Support Scotland. TCAT is a partnership between the Scottish Government, Macmillan Cancer Support, NHS Scotland, local authorities and third sector organisations that focuses on the care and support of people after treatment for cancer (http://www.gov.scot/Topics/Health/Services/Cancer/TCAT).

The overarching aims of TCAT are to:

- Enable people affected by cancer to play a more active role in managing their own care.
- Provide services which are more tailored to the needs and preferences of people affected by cancer.
- Provide more support to people affected by cancer in dealing with the physical, emotional and financial consequences of cancer treatment.
- Improve integration between different service providers and provide more care locally.
- Enhancing service integration and coordination and health and social care partnership working in relation to services for people affected by cancer

With a £5m investment from Macmillan Cancer Support for the national TCAT programme, NHS Lothian was successful in securing a Phase 1 bid to test a new recovery-based approach to cancer.
Background to NHS Lothian’s Phase 1 Pilot Project

The project design was informed by previous service user evaluations, site-specific patient focus groups and research work conducted in the Edinburgh Cancer Centre. This earlier work highlighted the challenges that people can face on completion of their treatment and unmet need. With this in mind we had an opportunity to ‘test out’ an end-of-treatment approach for patients across a range of tumour groups and evaluate the perceived benefits.

This project is in line with NHS Lothian’s clinical quality approach aimed at improving the delivery of a service that is responsive to patient need and supports people’s choices. It was not within the scope of the project to conduct an economic evaluation however from the patient evaluation, adopting a ‘pre-emptive’ approach to recovery was indicated to be clinically effective.

Aims and objectives

The overall aim of this pilot project was to evaluate the benefits of conducting a supportive end-of-treatment approach to recovery. The specific objectives included:

1/ Evaluating the implementation of Holistic Needs Assessment and care planning to support the identified needs of patients at approximately 6-12 weeks post treatment and again at 6 months.

2/ Agree a shared plan of care where the focus of the targeted advice and interventions were aligned with concerns as defined by the individual.

3/ Implement a summary of the consultation for the primary care teams, outlining the key concerns raised by patients along with any advice, interventions, referral or signposting that may have been offered.

4/ Evaluate the feasibility of embedding this service in everyday care.

5/ A secondary objective was to review the key concerns raised by all patients overall, and assess whether there were common themes for all patients, or within site-specific tumour group cohorts.

Project setting and procedure

The recovery clinics and consultations ran at the Edinburgh Cancer Centre, NHS Lothian or were conducted over the telephone depending on participant preference. Potential participants were approached by the site-specific Clinical Nurse Specialist (CNS) or Nurse Consultant (NC) and invited to participate in the project while attending their consultant follow-up clinic or by telephone.
An Information Sheet about the TCAT project was offered (Appendix I) and a Consent Form for the evaluation (Appendix II). On consent to participate, Diagram I details the recovery clinic design.

Diagram I

Prior to the recovery clinics the participants were invited to complete the Concerns Checklist and tick as many concerns as relevant to them (Rogers et al 2009) (Appendix III). The Concerns Checklist is a recognised tool for holistic needs assessment data and was designed as an aid to support clinical consultations\(^1\). The participants then identified their top 3 concerns for more in-depth discussion during the consultation. Both the participant and clinician then jointly agreed the key interventions/adaptive strategies, referral or signposting which were then summarised within a care plan (Appendix IV).

On completion of the consultation the participant was provided with a copy of the care plan. In addition a letter was written providing a summary of the clinic discussion, along with a copy of the care plan and sent to the General Practitioner.

The same process was followed for the 2\(^{nd}\) time point. At this time, for evaluation purposes, the participants were also asked to complete a purpose-designed Rapid Feedback Evaluation Form (Appendix V) to gather views on what worked well, not so well and any other comments on future developments for the clinics.

At the end of the recruitment period the participants were invited to attend a focus group, held at the Maggie’s Centre, Western General Hospital. A lead researcher, Gill Highet, from palliative care services at the Royal Infirmary of Edinburgh facilitated the session with the project manager, Mark Allardice

\(^1\)To ensure consistency in the use of the Concerns Checklist as an aid for consultation, the clinical team were provided with training from the clinical psychology team at the Edinburgh Cancer Centre. In addition all members had completed the Developing Practice Course- a toolkit for psychological support training.
acting as a scribe. The group was focused around 8 semi-structured questions (Appendix VI) that were developed from preliminary concerns checklist data and the rapid feedback evaluation.

**Methods**

**Participants and recruitment**

The recruitment period ran from November 2014 to October 2015. The participants were recruited from 4 tumour groupings and included:

- Patients treated with radical intent for lung cancer
- Patients who had completed radical pelvic radiotherapy treatment for cervical and endometrial cancer +/- adjuvant chemotherapy
- Patients treated radically and on completion of chemotherapy for Breast Cancer
- Patients who had completed radical pelvic chemo-radiation treatment for anal cancer and pelvic chemo/radiation and surgery for locally advanced rectal cancer.

Eligible participants were identified through their respective medical consultant clinics.

**Data collection**

Data collection included:

- Patient Concerns Checklist (Rogers et al 2009) (Appendix III) at 6-12 weeks after treatment and 3 months later
- A purpose designed rapid feedback form based on the principles of appreciative enquiry (Appendix V)
- Purpose-designed demographic checklist (Appendix VI)
- Additional audit data form (i.e. length of consultation etc) adapted from the Macmillan ‘one to one’ project conducted in Forth Valley (Appendix VII)
- A focus group interview at approx 6 months after completion of the interview to elicit the participants views of the clinics in supporting their recovery.
- The number of summary letters sent out to primary care to enhance communication.

**Project Evaluation**

**Internal evaluation – data analysis**

All demographic data and the Concerns Checklist data were entered on to an excel spreadsheet and analysed descriptively to include means, medians, total number of patients, percentages and significance where appropriate.

Comments from the rapid evaluation feedback tool and from the semi-structured focus group interviews were scrutinized and discussed with
colleagues then themed under agreed headings to provide a shared interpretation.

**External evaluation**
Macmillan Cancer Support have commissioned Edinburgh Napier University (ENU) to conduct the National TCAT evaluation. The Lothian Phase-1 TCAT project was already established and in progress prior to the National evaluation framework being devised. However the majority of core data required by ENU was collated retrospectively by the Lothian TCAT project manager in order to ensure that Lothian data is included within the National evaluation.

The Lothian Project Team also participated in two focus groups led by ENU. The data will be used to inform both the interim and final national project evaluation.

**Governance**

NHS Lothian Clinical Governance approval was sought and obtained for the project. Through this process ethical review was not considered to be a requirement.

A Lothian TCAT Steering Group was formed to oversee the monitoring and ongoing development of the project. This included key stakeholders from the different tumour groups, South/East Cancer Network (SCAN), patient representation, Macmillian Cancer Support representation, members from the Edinburgh Cancer Centre management team, NHS Lothian Strategic Planning and Finance, Primary Care and the City of Edinburgh Council Local Authority (Appendix VIII). The group met on a regular basis during the implementation and operational phase of the project. The day-to-day running of the project was overseen by the project Team (Appendix VIII). The Lothian TCAT Steering Group report in to the South/East Cancer Network (SCAN), who then report to the Regional Cancer Planning Group (RCPG), the Regional Cancer Advisory Group (RCAG), and the National TCAT Programme Board.

A Project Manager was appointed to oversee the running of the project and ensure clear lines of communication between all stakeholders and was in post for one year of the two year project. A Project Initiation Document (PID) was developed, containing the key elements of information required to direct and manage the project along with timescales and completion dates.

Regional and national reporting was achieved through submitting quarterly Project Highlight Reports to the SCAN Regional Group, and to the National TCAT Programme Board.

**Results**

Quotes from the participant feedback evaluation are integrated throughout the results section and support the findings identified from the concerns checklist.
**Recruitment**
A total of 82 patients were invited to take part in the pilot and 61 (74%) agreed to participate. The reasons that patients declined the service are listed in Table I (Appendix X) with the main reason being that they did not feel they were in need of the service or were already receiving support from other places (n=11).

Patients were recruited to the recovery clinic either face to face while attending their oncology review clinic (31 out of 38 approached - 82%) or via the telephone (n= 30 out of 39 approached - 77%), highlighting a similar uptake to both approaches.

“I appreciated being able to have a consultation on the phone when I couldn’t go to the hospital because of work…………may be something other people would appreciate to” (P58)

**Demographics**

**Age**

The median age of the participants was 58 years (range 35 – 80 years) representing a significantly younger group (p=0.01) than the non responders with a median age of 73 years (range 36-85).

**Diagnosis**

The breakdown of the different tumour groupings of the participants and non participants are viewed in Graph I with a higher proportion of patients with lung cancer declining participation (41%). This may be related to higher co-morbidities in this group.

**Graph I: Diagnosis of responders and non responders**
Gender

A higher percentage of the participants were women 52/61 (85%) which was also reflected in those who declined participation 17/20 (85%), however this can be accounted for by two of the four tumour groups being made up of female malignancies, both with higher recruitment numbers.

Employment status

The majority of patients who agreed to participate in the project were currently working n=35 (57.4%); followed by n=24 (39.3%) being retired; and n=2 (3.3%) patients who were unemployed. Of the 21 patients who declined, a higher percentage of people were retired n=11 (52.4%) with 7 (33.3%) of patients currently working and 3 (14.3%) unemployed.

Marital status

Table I shows the breakdown of marital status of the participants and non participants with the majority being married or in cohabitation n= 35 (57%). The exact reason for this in unknown, but similar to age where the responders were younger, any future work needs to target and consider perceived ‘harder to reach’ groups.

Table I: Marital status

![Marital Status Bar Chart]

Performance Status

Performance status is a measure of general well being and activities of daily living measured on a scale of 0-4 with 0 representing full activity ability and 1 being symptomatic but able to carry out light work. The majority of the participants were performance status 0 n=31 (51%) or 1 n=27 (44%). This result indicates that overall the participants were a ‘well’ group.
Concerns Check-List

Concerns
Complete data sets were available on 60 patients at Time-point 1 (TP1) and 57 patients at Time-point 2 (TP2). Table II lists the total number of concerns reported in each category.

Table II Total number of Concerns reported in each category

<table>
<thead>
<tr>
<th>Concern category</th>
<th>Number of patients at time point 1</th>
<th>Number of concerns at time point 1</th>
<th>Number of patients at time point 2</th>
<th>Number of concerns at time point 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>56</td>
<td>205</td>
<td>47</td>
<td>111</td>
</tr>
<tr>
<td>Emotional</td>
<td>32</td>
<td>75</td>
<td>28</td>
<td>41</td>
</tr>
<tr>
<td>Lifestyle</td>
<td>31</td>
<td>56</td>
<td>10</td>
<td>13</td>
</tr>
<tr>
<td>Practical</td>
<td>21</td>
<td>41</td>
<td>11</td>
<td>15</td>
</tr>
<tr>
<td>Family</td>
<td>14</td>
<td>18</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>Spiritual</td>
<td>4</td>
<td>4</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

The average number of concerns reported at TP 1 was 6.65 (range 1-22) which reduced significantly to 3.38 (range 1-20) by TP2 (p=0.00003). This reduction was also reflected in their overall concern scores where the participants were asked to indicate their overall level of concern on a scale of 0 (not concerned) to 10 (very concerned) which reduced significantly from an average of 4.79 at TP1 to 4 by TP2 (p= 0.04).

“*The Concerns Checklist was reassuring as it covered so many issues that were relevant to me, and the fact that they were on the list made me feel “normal”. XX (Clinical Nurse Specialist) is so approachable and understanding and knowledgeable…..*” P10

Looking in more detail, Table III provides the percentage decrease within the categories between TP1 and TP2, highlighting the greater decreases seen in reported lifestyle issues (78.5%) and practical issues (60.3%).
Table III Percentage decrease within the categories between time-point 1 and 2.

<table>
<thead>
<tr>
<th>Category</th>
<th>Average at time point 1 (range in brackets)</th>
<th>Average at time point 2 (range in brackets)</th>
<th>Percentage decrease</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>3.42 (0-11)</td>
<td>1.98 (0-9)</td>
<td>42.1%</td>
<td>0.00038</td>
</tr>
<tr>
<td>Practical</td>
<td>0.68 (0-5)</td>
<td>0.27 (0-3)</td>
<td>60.3%</td>
<td>0.011</td>
</tr>
<tr>
<td>Family</td>
<td>0.3 (0-2)</td>
<td>0.16 (0-2)</td>
<td>46.7%</td>
<td>0.084</td>
</tr>
<tr>
<td>Emotional</td>
<td>1.25 (0-6)</td>
<td>0.73 (0-5)</td>
<td>41.6%</td>
<td>0.02</td>
</tr>
<tr>
<td>Lifestyle</td>
<td>0.93 (0-5)</td>
<td>0.23 (0-2)</td>
<td>78.5%</td>
<td>0.00003</td>
</tr>
</tbody>
</table>

While we cannot assume the reduction in the number of concerns reported is a direct result of the recovery clinics, the patient feedback illustrates the benefit of discussion and advice. For example:

“It was beneficial to me to have the opportunity to discuss issues, concerns and general well being with someone who understands and can empathise with my condition and treatment. It was particularly reassuring to know I could contact the team if I had any concerns, the ongoing support is much appreciated. I received good advice and information with regard to diet and exercise” (P73)

“being able to discuss all of the issues facing me at the end of treatment; getting some good advice; finding out what happens next after treatment; taking stock and clarifying what to do next; well worth doing and hugely beneficial, thank you” (P52)

“This was excellent, to be able to talk face to face to an informed, skilled, experience nurse who fully appreciated everything discussed was for me invaluable. I really appreciated being advised, guided and listened to” (P33).

It was great to talk to someone knowledgeable (and very caring) once treatment for over. The small things that concerned me felt large because of my sense of vulnerability and it helped me to put things into perspective” (P58)

The overall total number of physical and emotional concerns reduced between time-point 1 and 2 but they remained the most frequently reported

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2 The category ‘Spiritual’ is omitted from the table as only 4 people reported these concerns at TP 1
with a slightly higher percentage reported out of all concerns at TP2 (physical: 51% TP1 and 58% TP2; emotional 19% TP1 and 22% TP2).

Again the patient feedback reflected what people found helpful from their discussions at the recovery clinics in trying to manage emotional and physical concerns, for example:

“I have felt incredibly supported by her (Clinical Nurse Specialist) during my recovery these last few months…a scarier time than during treatment, as it can be quite a shock going it alone” P83

“…Thought the clinics were a great stepping stone, once treatment finished I felt a bit stuck and alone. The clinic made me feel good and helped me jump start my brain to think of life, things beyond the chemo life and get started again. It was like a transition period” (focus group participant)

“knowing it’s not just me” (P6)

The participants were asked to select their top three concerns from the checklist for more in-depth discussion during the consultations at TP1 and TP2. The frequency of all issues that were raised are presented in Table IV (Appendix XI) with most common top three issues reported shown in Table V.

Table V Most common top 3 reported concerns

<table>
<thead>
<tr>
<th>Time point 1</th>
<th>Time point 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Tired/exhausted or fatigue (16)</td>
<td>• Worry fear or anxiety (12)</td>
</tr>
<tr>
<td>• Hot flushes and sweating (13)</td>
<td>• Tired/exhausted or fatigue (11)</td>
</tr>
<tr>
<td>• Worry fear or anxiety (13)</td>
<td>• Sleep problems or nightmares (8)</td>
</tr>
</tbody>
</table>

As a secondary objective of this project, we sought to look at whether the issues that were raised were common to all patients regardless of tumour type or whether they were disease specific. Overall the frequently reported issues of fatigue, worry and anxiety, sleeping difficulties were common to all. While the numbers were too small to make any real interpretation, the issues that were more specific to disease groupings included the following:

- ‘Appearance’ being a bigger issue for women with breast cancer (40%) than any other group
- 50% of patients with lung cancer reporting breathing difficulties as one of their top 3 concerns
- 40% of patients with lung cancer reported eating or appetite difficulties as a top 3 concern, higher than any other group
- 83% of patients concerned about work or education were 45-54 years old
- 31% of colorectal patients complained of tingling in their hands and feet which was higher than in any other group (likely to be chemotherapy related)

Advice and intervention

We then considered the type and frequency of interventions and advice offered to the participants to support them in managing the issues they raised. Table VI highlights symptom assessment and advice, along with assessment of emotional well-being being the most frequently reported followed by general exercise advice (sit less move more) and written information leaflets. The more targeted advice/interventions listed were specific to the tumour groups, for example the use of vaginal dilators in gynaecological and anal cancer and breathing techniques in lung cancer.

Table VI: Frequency of advice and interventions offered at time-point 1 and time-point 2

<table>
<thead>
<tr>
<th>Number of Patients</th>
<th>Time point 1 (frequency)</th>
<th>Time point 2 (frequency)</th>
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</thead>
<tbody>
<tr>
<td>43</td>
<td>Symptoms advice (f=91)</td>
<td></td>
</tr>
<tr>
<td>42</td>
<td></td>
<td>Symptoms Assessment (f=70)</td>
</tr>
<tr>
<td>39</td>
<td>Symptoms assessment (f=81)</td>
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<td>38</td>
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<td>Symptoms advice (f=61)</td>
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<td>30</td>
<td>Assessment of emotional well-being (f=51)</td>
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<tr>
<td>27</td>
<td>General exercise advice (sit less, move more) (f=45)</td>
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</tr>
<tr>
<td>23</td>
<td>Advice leaflets/information (f=36)</td>
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</tr>
<tr>
<td>18</td>
<td></td>
<td>General exercise advice (sit less move more) (f=18)</td>
</tr>
<tr>
<td>16</td>
<td>Dietary (healthy eating/diet) (f=23)</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td></td>
<td>Other (f=16)</td>
</tr>
</tbody>
</table>
From the patients feedback the perceived benefits from the discussion and advice offered are highlighted in the following quotes:

“listened well, helped in all areas of my life” (P19)

“…I really appreciated getting assistance to get help with post cancer ailments that are still being problematic even though treatment is finished” P8

“I learned that improving bowel function will help improve bowel control, so I’ve been motivated to persist with trying out medication to help that. I like knowing there’s someone I can turn to” (P75)

Referrals

From the recovery clinic consultations a number of referrals were made to other organisations, departments or healthcare professional which can be viewed in Table VII Appendix XII. Of note, seven of the 61 participants (11.5%) were referred to clinical psychology. As one patient described

“it’s good to have one person to meet and run through current issues after treatment. Really appreciate getting assistance to get help with post-cancer ailments that are still being problematic after treatment finishes” (P8)
Signposting

From the recovery clinic consultations many of the participants were signposted to other support organisations with Maggie’s Centre followed by the Macmillan Information Centre being the most frequent (Appendix XIII, Table VIII). Of note, there was an increase in the number of participants signposted to the Macmillan Move More Programme at time-point 2. While this was only 5 participants it is important to highlight it reflects the start of the programme within the Edinburgh leisure centers at that time.

Staff workload

The length of the recovery clinic consultations and any post consultations work (i.e. referral letters, GP letters etc) were recorded at TPI and TP2 (Table VIII). When combining the consultation and post clinic work, the total workload per participant averaged 70 minutes at TP1 with a slight reduction to 65.75 minutes at TP2.

Table VIII

<table>
<thead>
<tr>
<th>Workload</th>
<th>Average at time point 1 (range in brackets)</th>
<th>Average at time point 2 (range in brackets)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview</td>
<td>45.4 minutes (20-70)</td>
<td>37.5 minutes (20-60)</td>
</tr>
<tr>
<td>Post interview work</td>
<td>24.6 minutes (10-70)</td>
<td>20.35 minutes (10-50)</td>
</tr>
</tbody>
</table>

Recovery Clinic Summary Letters

Following all the recovery clinic consultations a summary of the meeting, including treatment and follow-up plans, along with a copy of the care plan was sent to the participants General Practitioner in 93.4% (57/61) of cases at TP1 and 91.4% (53/58) at TP2.

Rapid feedback form

Forty-nine rapid feedback evaluation forms were returned providing an 80% return rate. The evaluation form asked the following 3 questions:

1/ what aspects of the end of treatment recovery clinic worked well?
2/ what did not work so well?
3/ is there anything that could be done to improve the care you received?

The majority of the feedback related to Q1. The comments were themed under agreed headings to provide a shared interpretation and presented in Box I
Aspects of the end of treatment recovery clinics that were beneficial

The Concerns Checklist

Many of the participants liked that fact that the concern checklist helped them to focus on their key issues. It helped them in realizing they were not alone in the problems/issues that they were experiencing and this helped normalise what was happening. For example, feedback include comments such as “knowing its not just me”, “it covered so many issues that were relevant to me and the fact they were on the list made me feel normal”.

For some of the participants, they felt the checklist helped ‘pull’ everything together and gave them the opportunity to talk through issues that they had previously not felt able to do or may not have brought up otherwise, for example “completing the form highlighted all areas which might cause concern but also allowed me to list things I might have ignored and wished I had discussed”. They liked the fact the tool enabled them to discuss issues that might otherwise have seemed small or insignificant and the ‘holistic’ approach that benefitted different aspects of their life. For example one of the participants described “the project helped in all areas of my life” and for another “by filling in the form beforehand, it made me think more fully about all aspects of my recovery and treatment”.

The consultation

The majority of the participants felt that talking through their issues/concerns was beneficial. Some commented that they found the setting informal and relaxing and liked the fact the appointment was not rushed, for example “the unhurried appointment was so appreciated”; “I found this very helpful to be able to talk with someone who gives you time and cares”.

A number of the participants commented on the reassuring aspects that the recovery clinic brought, for example “you have got questions and they don’t always come out at the last clinic (medical follow-up appt) , a final reassurance was so important”. For others the consultation gave them a good perspective and the opportunity to get questions out of the way “the small things that concerned me felt large because of my sense of vulnerability and it helped me to put things into perspective”.

The Staff

Many of the participants commented on the reassurance they got from discussing their health issues with a clinical member of staff and their perception of that person being experienced, skilled and knowledgeable to deal with their concerns. For example, “it felt reassuring going over all health topics that were niggling….reassurance is what is needed and only a professional can do this”. Continuity and having a single point of contact was hugely beneficial to many of the participants which, for some helped them in feeling less ‘alone’ “I think the most important aspect was having a designated nurse who I could contact any time to discuss my concerns, just knowing XXX(CNS) was there should I need to talk is a huge relief”
In relation to the feedback on ‘what did not work so well’ and ‘anything that could have been done to improve the care you received’ there were very few comments and those that were made were generally related to other aspects of treatment/management including:

- Cleanliness of the ward environments
- Limited stoma nurse in-put post stoma formation
- Last day of chemotherapy being disorganised
- More specific help with returning to exercise
- Packs could be provided post chemotherapy of resources to access yourself

**Focus Groups**

Seven participants out of 13 who initially agreed to take part in the focus group interview participated. This included 4 participants treated for a gynaecological malignancy, 2 for lung cancer and one breast cancer. The feedback is summarized as ‘collective themes’ in Box 2. The ‘collective themes’ represent the perceptions of the service by all focus groups members.

**Box 2 Collective themes**

- The attendees stressed the importance of the clinics, the continuity of care and the expertise and empathy of the Clinical Nurse Specialists (CNS) – common words used were “trust”, “confidence”, “availability”, “empathy”.

- A common theme described related to the end of treatment with words such as feeling “lousy”, “high and dry” and “abandoned”, this was in spite of an expectation that end of treatment should have been a time of celebration. They felt the recovery clinic helped to ease the transition to a “new normal”.

- Several of the group also commented that the clinics helped them to “regain control” after treatment having felt out of control on occasions.

- The process of listing concerns, and realizing the extent of these concerns was highlighted, even although they had felt they “shouldn’t be bothering anyone” and that they felt “lucky to be alive”.

- The group agreed that their concerns changed from the first to the second clinics), and also reported feeling more confident at the second clinic.

- The group felt that a record of the conversation/outcomes was important in order to reflect on the discussion and acting as a prompt for their next clinic or appointment.
The group also stressed the importance of the cost/time benefit and efficiency to the NHS of holding the clinics, as the attendees felt discussing their concerns with a CNS made subsequent appointments quicker and more focused.

All participants strongly felt that the clinics should continue, would have liked to have had the opportunity to attend more than twice and would be willing to provide testimonials to back up their strength of feeling.

**Health Care Professional Feedback**

As part of the overall evaluation of the pilot project it was felt important to gather the views of the four health care professionals who conducted the recovery clinics. Their perceptions of the recovery approach are presented in Box 3.

**Box 3 – HCP perceptions of the recovery clinics**

- Provided the opportunity to really focus on individual issues and concerns and support people to develop strategies and find ways to overcome these issues or adapt to their situation.

- Perception of making an overall difference to the pathway and patient symptoms.

- Found the concerns check list a very useful tool in providing a ‘framework’ for people to highlight their concerns that they may not have done otherwise.

- Overall sense that the clinics helped people to move on and gain a sense of control back. There was also a number of individual examples of ‘rescue’ work where we picked up significant health-related issues that required immediate intervention.

- Important that HNA is not seen as a easy roll out, people need appropriate training in order to maximise that conversation or consultation with the person completing the tool.

- Requires appropriate clinical infrastructure in terms of clinical space and administration support (i.e. GP letters).

- It is additional work, averaging approx 70mins per person including the post consultation work i.e. GP letters, care plans, referrals etc. Overall, for a small investment upfront there is the potential to make savings longer term through pre-emptive recovery interventions/advice to support people to move on.
• Much greater knowledge of what is available for people in the community, through their local authorities, voluntary sector.

• Greater links with the other 2 TCAT Phase 2 projects starting up which are community based along with Macmillan’s vocational rehab and move more work

Discussion

The findings from this pilot Phase I project would suggest that by introducing an early pre-emptive recovery approach after cancer treatment we can see reductions and changes in the number of concerns and issues that people experience over time. The participant evaluation data would indicate that by identifying issues that are important to a person’s health and wellbeing and jointly working with them to manage their recovery through shared planning, a sense of control and confidence returns. This is similar to the findings from the recently published Scottish Cancer Patient Experience Survey highlighting that people who had a care plan had a markedly better experience than those who didn’t (http://www.gov.scot/Publications/2016/06/3957). The most frequently reported issues in this project related to physical and emotional concerns and while the overall total number of concerns reduced, many people were still reporting issues six months from treatment. Given the nature and intensity of the treatments that the participants received, many may live with the consequences of treatment for some months after treatment, and in a few cases, years. Therefore developing evidence in relation to the needs of people who survive cancer and the most effective models or services to support people is fundamental. We cannot categorically say that the overall reduction in the total number of concerns reported was a direct consequence of the recovery approach however the participant feedback has provided invaluable insights into their perceptions of what worked and how this intervention helped them to move on and adapt.

Normalising recovery

From our interpretation of the evaluation data, there is a sense that this approach helped to ‘normalise’ how the participants were feeling at the end of treatment and how the concerns checklist ‘allowed’ them to talk about issues that they may not have raised otherwise. In the focus group, the participants expressed how they had expected to feel elated after treatment but actually felt very flat and, in some incidences, frightened 'going it alone'. The recovery clinics appeared to offer a transition from the intensive hospital contact during treatment to recovery and moving forward in life.

Key concerns identified

Looking more specifically at the categories of concerns raised, the most frequently reported concerns were issues of fatigue/tiredness/exhaustion and worry/fear/anxiety and hot flushes and sweating in women. Acknowledging
that the total numbers of participants within each disease grouping is relatively small therefore we cannot generalise, the trend does suggest these concerns are common across all tumour groups (hot flushing to the female disease groups) within the first 6 months from treatment. We then looked at the advice and interventions offered with symptom and emotional assessment and advice being the most frequently reported to support the participants to manage the issues raised. This was followed by general advice on exercise and lifestyle. The more targeted interventions reported were specific to the tumour groups. It was not the intention of this project to ‘replace’ existing disease surveillance follow-up which is a fundamental component of management in the early stages from treatment, but rather to ‘compliment’ it. From the participant feedback this seemed to work well with people commenting on the helpfulness of the advice they received and, in some cases being given advice that enabled them to self manage with comments being made such as ‘feeling motivated’ and ‘re-gaining control’. A few of the participants commented on the clinics helping to give them ‘perspective’ at a time of vulnerability and felt this would enable them to be more focused in their subsequent follow-up appointments.

**Potential longer-term benefits**

One limitation of this project is the lack of comparison data therefore we do not know if the reduction in the number of concerns raised would have happened anyway with time or through seeking advice elsewhere. We also don’t know if this approach has provided a more efficient use of resource, for example a reduction in health and social care contacts. One could argue that there is in fact an additional cost when we look at the average length of additional CNS and NC time averaging approximately 70mins at TP1 and 65mins at TP2. However we do have compelling participant feedback data from both the rapid feedback evaluation form and focus group to suggest pre-emptive assessment and advice/interventions is important from both a clinical and quality perspective. Subjectively, the project team believe this pre-emptive supportive approach to recovery is also likely to have been efficient (with possible cost saving) by helping to minimise physical and emotional distress, enabling people to move forward and return to a degree of normality or ‘new’ norm. In addition, by supporting people to feel more ‘prepared’ in managing ongoing concerns, whether they are practical, physical or emotional, this in turn is likely to result in better adaptation and one’s ability to self manage and move forward. Equally it is also important to acknowledge the ‘rescue’ work this approach provided in ensuring timely referrals for a few of the participants who expressed significant vulnerability and the impact that had on their wellbeing and recovery.

**Clinical expertise**

In this project the recovery clinics were run by 3 CNS’s and 1NC all with considerable expertise in their specialty. Many of the participants commented on the importance of that person having knowledge, skill, expertise, empathy and caring skills. This finding is also in keeping with the recent feedback data from the Scottish Cancer Patient Experience Survey highlighting the important
role that specialist nurses have in ensuring patients are informed or signposted to appropriate services (http://www.gov.scot/Publications/2016/06/3957). Again from a clinical and quality perspective this is important however arguably this is also likely to have been a more efficient approach than existing systems that are not necessarily pre-emptive by having the right expertise at the right time to be able to manage the majority of the concerns raised. The challenge in terms of sustainability is having that small investment up front to be able release capacity to establish the recovery clinics across all disease groupings. Any future service development work would require some cost benefit analysis.

**Enhancing Integration**

One of the priorities of TCAT is to enhance service integration and coordination of after care and support. This pilot project was carried out in secondary care with a focus on concerns after cancer treatment and our data reflects this. However over the duration of the development, preparation and execution of the project we have seen a growing shift change and an increased awareness of the importance of integration as we progressed our approach to recovery. For example all our signposting was to the voluntary sector and in particular to Maggie’s Centre and the ‘where now course’ and the Macmillan Information Centre. Both these organizations were familiar to the project team but since starting the project we have become much more aware of other resources available such as Westerhaven, befriending schemes, Macmillan Move More. The Macmillan vocational rehabilitation service is now based in the Edinburgh Cancer out-patients and with such visibility, wider rehabilitation approaches are becoming much more at the forefront of a health care professional’s thinking. This cultural change is set to continue with the Phase 2 TCAT projects having now started with a focus on local authority and community which will provide an even greater opportunity for integration.

Finally the original aim of this pilot project was to evaluate the perceived benefits of introducing a recovery approach following treatment by identifying the issues that are important to that individual person. Since undertaking the project two reports have been published that describe one fundamental question to underpin discussions with patients “what matters to you”. These documents include Realistic Medicine (Scottish Government 2015) and Beating Cancer: Ambition and Action (Scottish Government 2016). By starting with the issues that matter and working with that person to support their choices we will enable people to be involved and more proactive in their recovery.

**Limitations/Challenges**

In the original funding application the intention had been to implement ‘end of treatment summaries’ as part of the project. However it became clear early on in the development of the project that this would take wider engagement with the site-specific multidisciplinary teams and this was out-with the scope of this project. However, recognising the important of maximising communications
between secondary and primary care team a letter outlining the consultation and ongoing follow-up arrangements along with a copy of the agreed care plan was sent to the patients General Practitioners at each visit.

**Ongoing work as a result of the project**

Based on the positive findings the project teams are looking at adapting this approach and embedding HNA’s in practice. Specific work includes:

- All patients with breast cancer on completion of chemotherapy and all patients treated with pelvic radiotherapy for anal cancer will be offered a one-to-one consultation, using a HNA to support them in their recovery. A telephone consultation will be offered to those who do not want to attend for a hospital visit.
- An educational event to highlight the benefits of HNA’s to CNS within the Cancer Centre
- A review of existing practices that support patients who experience late effects/consequences of pelvic treatment and to devise recovery referral pathways
- A review of existing clinical commitments and the feasibility of embedding recovery clinics within clinical sessions as part of job planning
- The project team will present the findings to the Edinburgh Cancer Centre’s Clinical Management Board for discussion around implementation and sustainability for all tumour groups
- Present findings to the SCAN TCAT Group and the TCAT Programme Board

**Recommendation**

Our recommendation is that this recovery approach is beneficial and should be considered for all tumour types with adequate infrastructure in place. However, this needs to be considered as part of NHS Lothian’s over cancer work plan.

**Future Plans**

- The project team will deliver educational sessions to ensure wider dissemination and facilitate discussion on the use and implementation of this approach within our services
- The project team will disseminate their findings through publication in nursing journals to ensure wide dissemination and shared learning across the UK
- The project team will continue to build and strengthen relationships across health and social care, local authority and the voluntary sector
and develop a NHS Lothian service directory of resources available to support people in their recovery from treatment

**Acknowledgements**

We would like to thank the following people: all members of the NHS Lothian TCAT Steering Group for their guidance; Brooke Marron (Medical Student) for her statistical advice and support with data analysis; Gill Highet (Lead Palliative Care Research, NHS Lothian) for facilitating the participant focus group; Ellen Hardie (Lead Physiotherapist for Cancer) for her support in developing exercise guidance for patients with cancer and finally, to all the participants who took part in the project and shared their invaluable insights, thank you.
References


Appendix I  Participant Information Sheet

Service Evaluation of the End-of Treatment Recovery Clinics and Needs Assessment – Information Sheet

Introduction

You have been asked to take part in this evaluation of the end-of-treatment recovery clinic and needs assessment. Before you decide if you want to take part, it is important for you to understand why the evaluation is being done and what it will involve. This sheet tells you why we are doing this evaluation, and how you might be involved. Please take time to read if carefully. Please ask if there is anything that is not clear or if you would like more information.

Why is this service evaluation being done?

We are trying to understand more about your experiences of attending the end-of-treatment recovery clinic. We are interested in your views on what has worked well, what worked less well and any ideas you may have for improvement to the service. The information you give will help the individual clinical teams to consider improvements or alterations to the service.

Why have I been chosen?

We would like to ask you to take part in this evaluation as you have recently attended the end-of-treatment recovery clinics. We are particularly interested in finding out about your experience of the service and if the advice and support provided at the clinics has helped you in your recovery.

What will happen if I agree to take part?

If you are willing to take part, at the end of your second end-of-treatment recovery clinic you will asked to complete a short questionnaire to find out what worked well and what could be done differently. You will also be invited to participate in a focus group interview at a later date to find out about your overall recovery experience in more detail.

After you have read this information sheet, had the opportunity to ask any further questions and consented to take part, an independent evaluator will ask you to complete the short questionnaire. He or she will then arrange a date and time for you to attend a focus group interview. The focus group will include a total of approximately 8-10 people who have all recently been attending the end-of-treatment recovery clinics. The interview will last between 30-45 minutes. We would like to record the interview to help us keep an accurate record of what you say.
Do I have to take part?

No. It is very much up to you whether or not to take part. What you decide will not affect your care in anyway.

What are the possible benefits and disadvantages?

Agreeing to take part may not help you personally, but the information we collect will hopefully help improve the care that people receive in the future by providing us with a better understanding of the issues that people can experience during their recovery period. You may find that a disadvantage of taking part is the commitment of time required for the interview. We have estimated that it should take no longer than 45 minutes. There will be no further commitment other than this.

Will my taking part in the service evaluation be kept confidential?

The recording of the focus group interview will not include any of your personal details. It will not be heard by anyone other than the team who are doing the service evaluation, and will be kept in a secure place. All of the information collected for the evaluation will be kept confidential. Data will be kept in a locked filing cabinet and backed-up on a secure computer. No names will be attached to the stored data.

Who should I contact for further information about the service evaluation?

Gillian Knowles
Nurse Consultant
Edinburgh Cancer Centre
Western General Hospital
Edinburgh EH4 1QA

0131 537 3793

Thank you for reading this information sheet.
**Appendix II**

**Evaluation Consent Form**

**Service Evaluation of the End-of Treatment Recovery Clinics and Needs Assessment**

---

**EVALUATION CONSENT FOR**

Please initial each box you agree to

<table>
<thead>
<tr>
<th><strong>• I have read and understand the information sheet for the evaluation and had the opportunity to ask questions.</strong></th>
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<tbody>
<tr>
<td><strong>• I understand that taking part is voluntary and that I am free to withdraw consent at any time, without giving any reason.</strong></td>
</tr>
<tr>
<td><strong>• I agree to completing a short evaluation questionnaire at the end of my second end-of-treatment recovery clinic.</strong></td>
</tr>
<tr>
<td><strong>• I agree to take part in a focus group interview for the above evaluation.</strong></td>
</tr>
<tr>
<td><strong>• I understand that this interview will be audio-recorded and give permission for this to occur.</strong></td>
</tr>
<tr>
<td><strong>• I understand that data from the anonymised questionnaire and extracts from the anonymised focus group interview may be published for evaluation and other academic purposes and give permission for this to occur.</strong></td>
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<td>Field</td>
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<tr>
<td>MARITAL STATUS</td>
</tr>
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<tr>
<td>DIAGNOSIS</td>
</tr>
<tr>
<td>DATE OF DIAGNOSIS</td>
</tr>
<tr>
<td>TREATMENT COMPLETION DATE</td>
</tr>
<tr>
<td>GENDER</td>
</tr>
<tr>
<td>CONSENTED TO PARTICIPATE</td>
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</table>

**IF NO PLEASE DOCUMENT REASON**

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

32
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<tr>
<th><strong>RECRUITED FROM</strong></th>
<th>Clinic □ By Telephone □ Other □ (please state):</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>________________________________________________</td>
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</tbody>
</table>

1/ INTERVIEW ONE DATE: ____________________________

GP summary letter YES □ NO □

2/ INTERVIEW TWO DATE: ____________________________

GP summary letter YES □ NO □

3/ COMPLETED RAPID FEEDBACK EVALUATION YES □ NO □

4/ ATTENDED FOCUS GROUP YES □ NO □

If no please give reason for declining: ____________________________

______________________________________________________________

______________________________________________________________

5/ DID YOU USE AT HAD TOOL AT EITHER OF THE INTERVIEWS ?

YES □ NO □ DATE__________

6/ CURRENT LIVING SITUATION

Living alone
Living with spouse/partner
Living with children/relatives
Living with friends
Living in sheltered/nursing home
Other
Not Known

7/ PERFORMANCE STATUS

1 Fully active, able to carry on all pre-disease performance without restriction
2 Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature
Abulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours

4 Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair

6/ DOES THE PATIENT CONSENT TO BEING SENT A NAPIER UNIVERSITY FEEDBACK QUESTIONNAIRE?

YES ☐

NO ☐
Appendix IV  Concerns Checklist

Appendix V  Rapid Feedback Form

Evaluation of your experience of the end of treatment recovery clinics

1. Can you tell us what aspects of the end of treatment recovery clinics worked well?

2. What did not work so well?

3. Is there anything that could have been done to improve the care you received?

Thank you very much for completing this questionnaire
Appendix VI  Care Plan

TCAT PROJECT
Recovery Clinic– Patient Concerns Checklist and Care-plan audit

Patient Code: Patient’s CHI No.

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<thead>
<tr>
<th>Agree to Participate</th>
<th>DROP down Menu to include:</th>
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<tr>
<td>Yes ☐ No ☐ If No - reason</td>
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<tr>
<td></td>
<td>Other ............</td>
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<td></td>
<td>NEED TO ADD TO</td>
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<th>Date of Concern Checklist completion</th>
<th>Enter below the number of concerns raised by the patient for each category ▼</th>
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<tr>
<td><strong><strong>/</strong></strong>/______</td>
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<td></td>
<td>Practical</td>
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<tr>
<td></td>
<td>Family/relationship</td>
</tr>
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<td></td>
<td>Emotional</td>
</tr>
</tbody>
</table>

Time-point 1 ☐ Time-point 2 ☐
Length of Interview (10 min drop downs)
Length of post interview wk (10 min drop downs)
### TOP 3 CONCERNS LISTED

**Concern 1 (might need to include a drop down to include no concerns documented)**

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<tr>
<th>Category (drop down descriptors)</th>
<th>Description (Drop down)</th>
<th>Level (drop down)</th>
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</thead>
<tbody>
<tr>
<td>Physical</td>
<td>i.e. descriptors for each category</td>
<td>1 (score 0-3 mild)</td>
</tr>
<tr>
<td>Practical</td>
<td></td>
<td>2 (score 4-6 moderate)</td>
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<tr>
<td>Family/relationship</td>
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<td>3 (score 7-10 significant)</td>
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<tr>
<td>Emotional</td>
<td></td>
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<tr>
<td>Spiritual/religious</td>
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<tr>
<td>Lifestyle or information</td>
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</tbody>
</table>

Was there a documented care plan  
Yes ☐  No ☐

**Key interventions/advice given (drop down)**

- Symptoms assessment
- Symptoms advice
- Assessment of emotional well-being
- General exercise advice (sit less, move more)
- Dietary (healthy eating/diet)
- Smoking cessation
- Breathing techniques
- Relaxation techniques
- Sexuality/sexual function
- Vaginal dilator advice
- Menopausal advice
- Body Image adaptation
- Advice leaflets/information  
  Please state what was given..............................................................
### Perceived Benefit by Patient

<table>
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<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

*Macmillan  What to do after Cancer Treatment Ends 10 top tips*

#### Referrals (drop down)

- Clinical Psychology
- Macmillan Benefits Advice Team
- Macmillan Grant Submission
- Social Services
- Working Health/Vocational Rehabilitation
- Smoking Cessation Programme
- General Practitioner
- District Nursing Team
- Dietician
- Physiotherapy
- Breast Cancer Care – Moving Forward Programme course
- Menopause Clinic (old Dean clinic)
- Psychosexual Health (old Dean Clinic)
- GP
- Stoma care team
- Erectile Dysfunction Clinic
- Breathlessness clinic
- Travel Concessions
- Complementary services
- Other Medical Speciality (please specify i.e. stoma team; erectile dysfunction clinic etc)
- Other.....please specify

#### Signposting (drop down)

- Macmillan Information Centre
- Maggie’s Centre (general)
- Maggie’s Centre Where Now Course
- Westerhaven
- Macmillan Move More Programme
- Edinburgh Leisure
- Dragon Boating (South Queensferry)
- General Physical activity resources (in Ellen’s List)
- Bowel Cancer UK
- Local Support Group
- Voluntary organisations (please specify........)
- Other.....please specify
Appendix VIII  Semi-structured focus group questions

1/ Thinking back, what were the most beneficial aspects for you personally of going along to the two clinics?
2/ Was it important that there were two clinics – one a couple of months after treatment, the other around 6 months?
3/ Was there a difference in what your issues and concerns were at these two time points? In what ways?
4/ Can you tell me a little about how the assessment process worked?
5/ To what extent did your participation in these clinics make you feel reassured about your future health and well-being? What was it that contributed to this?
6/ Was anyone referred on for support to another organisation? How did that go?
7/ Which bits do you think we did particularly well? Anything we could do differently or a little better?
8/ Any final comments about what difference coming along to the clinics made to you?
Appendix VIII  NHS Lothian Steering Group Members –

Martyn Oakly – Patient Representative
Mark Allardice – TCAT Project Manager
Elaine Anderson – Clinical Director, Western General
Sandra Bagnall – SCAN Patient Involvement Manager
Bill Clark – Macmillan Consultant
Diana Borthwick - Clinical Nurse Specialist, Lung Cancer
Sineaid Bradshaw – Lead GP, Westerhaven
David Cameron - Director of Cancer Services
Angela Edgar – Paediatric Consultant, RHSC
Karen Edwards – Specialist Physiotherapist
Elizabeth Preston – SCAN TCAT Clinical Lead
Shirley Fife – Macmillan Cancer Lead Nurse
Fiona Sneddon – Macmillan TCAT Representative
Jenny Fleming – Service Manager, Western General
Alison Hume - Clinical Nurse Specialist – Breast Cancer
Alasdair Innes – Nurse Specialist
Gillian Knowles - Nurse Consultant in Cancer
Lorna Porteous – Lead GP in Palliative Care
Jo McGinty - Clinical Nurse Specialist – Gynaecological Cancer
Peter McLoughlin – Strategic Programme Manager
Alan McNeill - Consultant Urological Surgeon
Morag Barrell – TCAT Co-ordinator, Midlothian Council
Nisreen Badiozzaman – Macmillan National TCAT Co-ordinator
Simon Malzer – Cancer Experience Panel Representative
Tom Welsh – Strategic Manager, Midlothian Council
Ellen Hardie – Project Physiotherapist, Edinburgh Cancer Centre

Project Team

Mark Allardice (TCAT Project Manager)
Gillian Knowles (Nurse Consultant/Joint Project Lead)
Diana Borthwick (Clinical Nurse Specialist, Lung Cancer)
Jo McGinty (Clinical Nurse Specialist, Gynaecological Cancer)
Alison Hume (Clinical Nurse Specialist, Breast Cancer)
Appendix X
Table I Reasons given for declined participation in pilot

<table>
<thead>
<tr>
<th>Reason for declining</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did not feel like they were in need of the service being offered</td>
<td>9</td>
<td>42.8%</td>
</tr>
<tr>
<td>Travel/ mobility issues</td>
<td>5</td>
<td>23.8%</td>
</tr>
<tr>
<td>Already receiving support from other services</td>
<td>2*</td>
<td>9.5%</td>
</tr>
<tr>
<td>No reason given</td>
<td>2</td>
<td>9.5%</td>
</tr>
<tr>
<td>Initially agreed, but did not attend future appointments</td>
<td>2</td>
<td>9.5%</td>
</tr>
<tr>
<td>Did not want to attend any more appointments at the hospital</td>
<td>1</td>
<td>4.8%</td>
</tr>
</tbody>
</table>
## Appendix XI – Table IV Frequency of top 3 concerns reported

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Time point 1</th>
<th>Time point 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>16</td>
<td>Tired/exhausted or fatigue</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>1. Hot flushes and sweating</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Worry fear or anxiety</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Pain</td>
<td>□ Tired/Exhausted or fatigue</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Worry, fear or anxiety</td>
</tr>
<tr>
<td>8</td>
<td></td>
<td>• Sleep problems/nightmares</td>
</tr>
<tr>
<td>7</td>
<td></td>
<td>• Tingling in hands/feet</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Hot flushes/sweating</td>
</tr>
<tr>
<td>6</td>
<td></td>
<td>• Pain</td>
</tr>
<tr>
<td>5</td>
<td>• Sadness or depression</td>
<td>My appearance</td>
</tr>
<tr>
<td></td>
<td>• My appearance</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>• Breathing difficulties</td>
<td>• Sadness or depression</td>
</tr>
<tr>
<td></td>
<td>• Dry, itch and sore skin</td>
<td>• Money or housing</td>
</tr>
<tr>
<td></td>
<td>• Eating and appetite</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Exercise and activity</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Insurance or travel</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Money or housing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Sun protection</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Tingling in hands and feet</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>• Constipation</td>
<td>• Work and education</td>
</tr>
<tr>
<td></td>
<td>• Diet and nutrition</td>
<td>• Other</td>
</tr>
<tr>
<td></td>
<td>• Difficult making plans</td>
<td>• Memory or concentration</td>
</tr>
<tr>
<td></td>
<td>• Getting around (walking)</td>
<td>• Diet and nutrition</td>
</tr>
<tr>
<td></td>
<td>• Loneliness/isolation</td>
<td>• Constipation</td>
</tr>
<tr>
<td></td>
<td>• Loss of interest/activities</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Memory or concentration</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Other</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Other friends/relatives</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Sleep problems/nightmares</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Taste/sight/hearing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Work and education</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Work and education</td>
<td></td>
</tr>
</tbody>
</table>
| 2 | • Anger and frustration  
• Diarrhoea  
• Sexuality  
• Sore or dry mouth  
• Support groups  
• Swollen tummy or limb  
• Unable to express feelings | • Taste/sight/ hearing  
• Loss of interest/activities  
• Loneliness or isolation  
• Insurance or travel  
• Getting around (walking)  
• Exercise and activity  
• Eating or appetite  
• Diarrhoea  
• Breathing difficulties |
| 1 | • Complementary therapies  
• Indigestion  
• Not being at peace with or  
• Feeling regret about the past  
• Partner  
• Passing urine  
• Smoking  
• Transport or parking  
• Washing and dressing  
• Wound care after surgery | • Anger of frustration  
• Dry, itchy or sore skin  
• Indigestion  
• Other relative/friends  
• Sexuality  
• Sore or dry mouth  
• Sun protection  
• Swollen tummy or limb  
• Wound care after surgery |
### Appendix XII – Table VII Frequency of referral made at time-point 1 and time-point 2

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Time point 1</th>
<th>Time point 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>Other</td>
<td>Other</td>
</tr>
<tr>
<td>8</td>
<td></td>
<td>Clinical psychology</td>
</tr>
<tr>
<td>6</td>
<td>Breast Cancer Care – Moving Forward Programme course</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>□ Clinical psychology □ General practitioner</td>
<td>GP</td>
</tr>
<tr>
<td>4</td>
<td>• Menopause clinic</td>
<td>Menopause clinic</td>
</tr>
<tr>
<td></td>
<td>• Macmillan benefits advice</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>• Macmillan grant submission</td>
<td>• Macmillan grant submission</td>
</tr>
<tr>
<td></td>
<td>• Physiotherapy</td>
<td>• Complementary services</td>
</tr>
<tr>
<td>1</td>
<td>• Breathlessness clinic</td>
<td>• Macmillan benefits advice</td>
</tr>
<tr>
<td></td>
<td>• Other medical specialty (stoma team, erectile dysfunction etc)</td>
<td>• Physiotherapy</td>
</tr>
<tr>
<td></td>
<td>• Working health/ vocation rehabilitation</td>
<td>• Breathlessness clinic</td>
</tr>
<tr>
<td></td>
<td>• Smoking cessation</td>
<td>• Other medical specialty (stoma team, erectile dysfunction etc)</td>
</tr>
<tr>
<td></td>
<td>• Stoma care team</td>
<td>• Working health/ vacation rehabilitation</td>
</tr>
</tbody>
</table>
### Appendix XIII Table VIII Frequency of Signposting at time-point 1 and time-point 2

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Time point 1</th>
<th>Time point 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>28</td>
<td>Maggie’s centre (general)</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Macmillan information centre</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Maggie’s centre (general)</td>
<td>Maggie’s centre (general)</td>
</tr>
<tr>
<td>13</td>
<td>Maggie's centre where now course</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td></td>
<td>Macmillan move more programme</td>
</tr>
<tr>
<td>4</td>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
<td>Other</td>
</tr>
</tbody>
</table>
| 2         |               | • Voluntary organisations  
|           |               | • Westerhaven |
| 1         | • Westerhaven  
|           | • Macmillan move more programme  
|           | • Edinburgh leisure | • Macmillan Information Centre  
|           | | • Edinburgh leisure |