Transforming Care After Treatment (TCAT)  
Phase 2

Integrated Community Cancer Care (ICCC) Project

Final report

May 2017
Executive Summary

The purpose of this report is to outline the aims, findings and recommendations of the Integrated Community Cancer Care (ICCC) Project, funded by Macmillan Cancer Support as part of the Transforming Care After Treatment (TCAT) programme, which started in 2013.

The aims of the project were:

- To develop an integrated pathway for people affected by cancer and their carers.
- To test the role of the Local Area Co-ordinator, (LAC) role in supporting people affected by cancer and their carers, within the integrated pathway.
- To develop a Cancer Champion network.
- To raise the profile of cancer care within the Health and Social Care Partnership.
- To identify how to sustain a successful integrated pathway after funding from Macmillan Cancer has ended.
- To provide data to Napier University so they can complete an independent evaluation of the whole TCAT programme for Macmillan Cancer Support. To provide that data it was necessary to use the Holistic Needs Assessment, (which is a Concern Checklist and associated care plan which Macmillan Cancer Support sanctioned us to use).
- The Holistic Needs Assessment is used more commonly in a clinical setting. Using it in a community setting provided the opportunity to test how effective it was to have one form that could be used and shared by clinical and non-clinical staff, if the person affected by cancer or their carer, consented to that.

In year two of the ICCC Project there were further discussions with Macmillan Cancer Support on further investment in Fife as part of the Macmillan Improving Cancer Journey (ICJ). Fife Health and Social Care Partnership, (H&SCP) has been awarded further investment from Macmillan. The ICJ Fife Service will start subsequently summer 2017, for 3 years.

The vision for the Fife ICJ service is to build on the success of the ICCC project and ensure that everyone diagnosed with cancer in Fife can easily access all the support they need, as soon as they need it, to enable them to live as well and as independently as possible.

The ICCC Project collected data via questionnaires from people aged 16 years and over who are or have been affected by cancer and also from those caring for a family member with a cancer diagnosis. The project team broadened the remit of the project by opening referral routes to people who were at any stage in their cancer journey instead of those who had
completed their cancer treatment as it became evident that individuals could benefit from the LAC role whenever required thus offering a more tailored and responsive service.

The main findings from the evaluation of the ICCC project were as follows;

- Referral routes were opened from the beginning of April 2016 and the project team received 183 referrals in the first year which ran from April 2016 until the end of March 2017. 165 Service Users referrals and 18 Carer referrals were made to the service. Of those referrals, 113 Service Users and 18 Carers were seen by a Local Area Co-ordinator (LAC). The 52 Service Users who did not see a LAC were either too ill, in hospital, deceased or did not feel they required the service at the time of referral.
- The LAC role has been proven to be a valuable asset within the Cancer Care Pathway by offering time, supported navigation and a strength based, person centred approach which has enabled people affected by cancer to use their increasing confidence to progress into a more self-managed cancer journey and carers to find the information and support which is right for them.
- The Holistic Needs Assessment has been a valuable person centred tool and when used in the community setting by non-clinical professionals has offered people affected by cancer the opportunity to consider their whole situation and wellbeing with the focus on social, financial, emotional and other every day concerns which are not necessarily medical concerns.
- The Cancer Champions network has developed during the life of the project to be an integrated network of sharing and learning with a clear aim of improving services for People Affected by Cancer. The group are working towards a sustainable future through the hosting skills of Fife Voluntary Action and the inclusion of third sector cancer organisations.
- The integrated framework of the Fife TCAT projects has allowed a collective approach to raising the profile of cancer and has developed a good foundation for the continual development of the cancer strategy in Fife.

The Recommendations, based on the outcomes from the ICCC project, are as follows;

1. The ICJ Project will build on the successful outcomes and learning from testing the role of the LAC within the TCAT ICCC project. Therefore the ICJ service will include LAC’s and the principles of the LAC approach.
2. The transition from the TCAT ICCC project to the ICJ service will need to be as seamless as possible to reduce the risk of disruption to the established pathway.
3. Development of an effective communication strategy is crucial to achieve this.
4. That the ICJ service continue the LAC Carer work as this has been a successful element of the TCAT ICCC project and the level of information and supported navigation, specifically for Carers whose family member has cancer, has been valued.
5. That the ICJ identify meeting points/clinics in each locality of Fife, or different localities across Fife. This will allow the LAC’s to see more people at a central, easily accessed point, (a benefit for people affected by cancer who cannot travel long distances) and thereby increase the amount of people the LAC’s can see. Home visits will still be necessary for some Service Users but this can be worked out on a case by case basis.

6. Introduce more follow up phone contacts to increase capacity of the LAC role. This approach will need be monitored to ensure that it does not detrimentally impact the highly valued person centred approach, which has been evidenced in testing the LAC role with people affected by cancer.

7. People affected by cancer were able to self-refer ICCC Project. Otherwise they had to give consent for a third party to refer on their behalf, (ie clinical nurse specialist, allied health professionals). This is described as an “opt in” referral system. The preferred option would be an “opt out” referral systems and it is recognised that this will be explored as part of ICJ. It is recommended to continue with the current “opt in” referral route until any further enhancements to referral pathways are agreed.

8. Work has begun to add the local knowledge of community cancer services into Fife’s local information website, “On Your Doorstep”. This will extend to include this information on the national NHS Inform website and directory to ensure that the wider population and networks can access this information. However, further expansion of the LAC role into community capacity building will further increase knowledge of services and assets within communities and identify gaps that might exist within different localities.

9. Continuation and development of the work achieved through the Fife TCAT Patient/Carer Reference Group. While this group will no longer exist as TCAT phases 1 and 2 come to an end in Fife, it is recommended that the group’s legacy helps shape the inclusion of “User Representative” involvement in the ICJ project.

10. Continued involvement in the Cancer Champion Network, which will sit within the third sector, to promote sharing and learning in Fife within an integrated Cancer network.

11. Continuation of integrated partnership working at a strategic and operational level with a commitment from all parties to work towards permanent long term vision for the transformation and integration of Cancer services in Fife.
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People Affected by Cancer who have been involved with the project and given permission to use their conversations in the project reporting.
Sharon Breeze and Mary Lynch (ICCC LACs)
Lucy Johnston and Brooke Marron, Edinburgh Napier University
Introduction

Setting the scene
In 2015 there were 2.5 million people living with cancer in the UK. Also, according to the Macmillan Cancer Support 2015 Statistics Fact Sheet, “the number of cancer survivors in the UK is projected to increase by approximately one million per decade from 2010 to 2040; resulting in four million people living with cancer in 2030”. Figures released by Cancer research UK in 2016, report that 1 in 2 people born after 1960 in the UK will be diagnosed with some form of cancer during their lifetime.

The Scottish Government set out their priorities for the predicted increase in cancer diagnosis and survivorship by publishing the Cancer Strategy “Beating Cancer; Ambition and Action”. This strategy identifies that, “over 40% of people in Scotland will be diagnosed with cancer during their lifetime….the number of people being diagnosed with cancer continues to rise”. The rate of cancer diagnosis is on the increase as are the number of people aged 75 and older however, the survival rates of cancer and other long term health conditions are also on the increase.

In Fife the trends are similar. Between 2012 and 2037 it is estimated there will be an increase of 93.47% of people aged 75 years and over in Fife, (information sourced through Macmillan Cancer Support). NHS Fife’s Clinical Strategy (published January 2016) reported that “the number of cancers diagnosed in Fife each year is projected to increase by a third. In 2008-12 there were 153,000 cancers diagnosed. This is projected to increase to over 204,000 by 2023-27”.

The National Cancer Survivorship Initiative (NCSI) publication “Adult Survivorship; From Concept to Innovation”, recognised that a “one size fits all” approach to cancer care is unable to offer, “patient centred outcomes”, to people with a cancer diagnosis and that cancer services should be looking to enable cancer survivors to live as healthy and as good quality lives as possible.

The changing demographics in Scotland have also contributed to the reform in Health and Social Care through The Public Bodies (Joint Working) (Scotland) Act 2014 and the associated quality framework of the National Health and Wellbeing Outcomes (see Appendix one) which have been put into place to improve the quality and consistency of outcomes for people in Scotland.
Background
The Transforming Care After Treatment (TCAT) programme has evolved to ensure that as the number of people living with cancer increases, they have support to deal with the physical, emotional and financial impact of cancer, even when treatment has ended. By promoting a self-management approach, people affected by cancer are empowered to take control of their care and receive services that are co-ordinated, tailored and responsive to their individual needs. The TCAT programme aims to test transformational service re-design and improve the integration of Health and Social Care.

The TCAT Programme is in three phases. Phase one were for NHS Boards and phase for Local Authorities, with the intention that a phase 2 bid be made by a local authority which would build and compliment an NHS Board phase 1 project. There have been 25 TCAT projects funded by Macmillan Cancer Support across Scotland in phases one and two.

NHS Fife secured funding for two phase one projects and Fife Health and Social Care Shadow Boars secured funding for one phase two project. The detail is below;

- Best Supportive Care for Lung Cancer Project (Phase 1), NHS Fife
- Melanoma Project (Phase 1), NHS Fife
- Integrated Community Cancer Care (ICCC) Project for all cancer types (Phase 2), Fife Health and Social Care Partnership

Integrated Community Cancer Care (ICCC) Project
The ICCC Project received funding of £96,000 from Macmillan Cancer Support which started in July 2015. The early planning work recognised the need to work with the NHS phase 1 projects as well as 3rd sector partners.

The overall aim of the project was to contribute to the development of an integrated cancer care and support pathway, the development of which is informed by the holistic needs of people affected by cancer.

It was also important that ICCC project aligned to the nine health and wellbeing outcomes. These are referred to later in the report within the case study.

The individual project aims were to;

- Develop and test an integrated cancer care pathway
- Test the Local Area Co-ordination approach within community cancer care
- Develop a Cancer Champion network
- Raise the profile of cancer within the health and social care partnership
- Contribute to the development of the NHS Fife Clinical Strategy in relation to cancer. You can view this strategy by using the following address;

- Strive to achieve a sustainable working model

The ICCC operational project team comprised of a project manager and 1.5 LACs (the LAC funding was sourced from the Integrated Care Fund for one year initially). As outlined in the project aims and objectives, a large focus of the project was to create and develop a pathway for people affected by cancer including carers and family members which involved local area coordination approach.

The LAC approach differs to other approaches within cancer care. The LAC specialises in working with individuals using a strength based, assets person centred approach; working alongside the person to identify “what matters” to them, creating an individualised plan which empowers the person to identify resources they can use to improve their confidence to increase their self-management skills.

**Referral Routes**

The ICCC project was designed to link in with both TCAT phase one projects; to work together both strategically and operationally but also to offer a direct referral route to both projects. Initial scoping work into the phase one projects identified the limited referrals that would be expected from both as the patients coming through the Melanoma projects did not appear to be identifying many concerns through the Holistic Needs Assessment (HNA) (see appendix two) and the patients coming through the Lung project were very near to end of life. Further scoping work consisted of meeting people across Fife with a cancer or who had survived a cancer diagnosis. They highlighted their experiences of their own cancer journeys but also the experiences of their family members. This scoping exercise highlighted the need to identify a third referral route, (routes one and two being from the lung and skin projects) and this third referral route to open up the potential for referrals from people with all kinds of cancer.

This was achieved by working with the Social Work Contact Centre to develop a script to ask people aged 16 years and over, who were either self-referring or being referred by another agency,( such as NHS Fife; third sector agencies; Fife Sports and Leisure Trust), if they would like to be contacted by the ICCC Project.

The third referral route saw a change of direction for the ICCC project as the emphasis then moved from being entirely on people who had finished treatment and opened it to people at any stage in their cancer journey from survivorship to diagnosis to end of life.

The project received over 180 referrals. As depicted in table 4 (page 22), Fife Council Contact Centre was the main referrer followed by the Community Palliative Care Nurses. The project received a number of referrals for service users with palliative care needs which
impacted on the data collection and evaluation of data as this required analysis of questionnaires, which a number of people were too frail to complete.

The project team adopted the use of the National Cancer Survivorship Initiative/Macmillan Survivorship pathway to map where an individual was on their cancer journey. The Survivorship pathway is shown in appendix three and will be discussed later in the report.

Holistic Needs Assessment (HNA)
It was reported in Macmillan’s Scottish Cancer Patient Experience Survey that one of the key factors in having a good experience as a cancer patient is having a care plan and without a care plan the patient is less likely to get their psychological, emotional and physical needs met. The IC CCC project adopted the Macmillan concerns checklist which is a holistic needs self-assessment and is completed on the initial visit to identify the concerns that the person affected by cancer has and also as a discussion document that leads to the co-production of an action plan/care plan.

The IC CCC Service User Journey
The IC CCC Service User Journey diagram (Diagram 1) below demonstrates the journey that the person affected by cancer makes with the LAC from referral to end goals.
The follow up work was seen to be just as important to ensure that individuals were enabled to access services at their own pace. The number of follow up contacts is based on individual circumstance and is not prescriptive.

Methodology and Project Findings

To understand the value the ICCC project had on the wider cancer care pathway, data was collected from the people affected by cancer and carers regarding their experiences both before and after contact with the ICCC project.

There were 3 main data collection streams; the core data, the 4 questionnaires for people affected by cancer and lastly the carers data. Data about carers is analysed later in this section of the report.

In addition, Macmillan Cancer Support commissioned Napier University to undertake an independent evaluation of the whole TCAT programme.

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.

Core Data (N=130)

Napier University advised of a core data set which they required to complete their independent evaluation. The core data set is contained within table 1, (gender, age, current living situation, economic activity, SIMD quintiles and diagram 2 cancer type). It was agreed at the start not to include carers in the core data set. The core data for the cohort of 130 Service Users has been outlined in the table 1.
It is notable that there were almost equal numbers of men and women and also that 64% were retired with the average age being 68 years and 35% being 75 years or over.

The youngest person referred to the project was 17 years and the oldest person referred was 97 years which demonstrated the breadth of knowledge required of the LAC’s.

Looking at the SIMD index against the cases referred there is a 9% difference between the most and least deprived people coming to the project. If adding percentiles 1 and 2, (which are the two most deprived) and then similarly adding percentiles 4 and 5 (which are the least deprived), then the gap of difference opens further, to show that 48% of referred cases were in the most deprived areas and only 29% were in the highest banding. The middle percentile (3) had 23% of people referred to the service. Whilst these figures reflect the known population demographics in Fife and are therefore not surprising, the figures start to allow us to build up an understanding of the varied backgrounds of the people affected by cancer who used the ICCC project.

### Table 1

<table>
<thead>
<tr>
<th>Core Data</th>
<th>Number (percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>69 (53%)</td>
</tr>
<tr>
<td>Male</td>
<td>61 (47%)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>Average age</td>
<td>68 years old</td>
</tr>
<tr>
<td>Under 65 years</td>
<td>49 (38%)</td>
</tr>
<tr>
<td>65 years to 74</td>
<td>34 (26%)</td>
</tr>
<tr>
<td>75 years and over</td>
<td>46 (35%)</td>
</tr>
<tr>
<td>Unknown age</td>
<td>1 (1%)</td>
</tr>
<tr>
<td><strong>Current living situation</strong></td>
<td></td>
</tr>
<tr>
<td>Living Alone</td>
<td>52 (40%)</td>
</tr>
<tr>
<td>Living with spouse/partner</td>
<td>60 (46%)</td>
</tr>
<tr>
<td>Living with Children/relatives</td>
<td>10 (8%)</td>
</tr>
<tr>
<td>Not Known</td>
<td>8 (6%)</td>
</tr>
<tr>
<td><strong>Economic Activity</strong></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>9 (7%)</td>
</tr>
<tr>
<td>Self Employed</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>2 (2%)</td>
</tr>
<tr>
<td>Long Term Sick/Disabled</td>
<td>29 (22%)</td>
</tr>
<tr>
<td>Retired</td>
<td>83 (64%)</td>
</tr>
<tr>
<td>Not Known</td>
<td>6 (4%)</td>
</tr>
<tr>
<td><strong>SIMD quintiles</strong></td>
<td></td>
</tr>
<tr>
<td>1 (most deprived)</td>
<td>27 (21%)</td>
</tr>
<tr>
<td>2</td>
<td>35 (27%)</td>
</tr>
<tr>
<td>3</td>
<td>30 (23%)</td>
</tr>
<tr>
<td>4</td>
<td>23 (18%)</td>
</tr>
<tr>
<td>5 (least deprived)</td>
<td>15 (12%)</td>
</tr>
</tbody>
</table>
The ICCC project worked with people affected by any cancer type and therefore a range of cancer types have been recorded from the core data. The diagram below highlights that lung (not best supportive care), breast and prostate cancer were the most common cancer types of the people referred to the project which is in line with the national cancer statistics.

Diagram 2

4 questionnaires for people affected by cancer

Data was also collected through questionnaires (see table 2) which offer both qualitative and quantitative information. The questionnaires collected basic data about the individuals and about their experience within their cancer journey.

Table 2

<table>
<thead>
<tr>
<th>Questionnaire Used</th>
<th>Rationale for use of specific Questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre TCAT Involvement</td>
<td>Used to document a base line of the individual’s experience of the cancer journey before LAC involvement (see appendix four)</td>
</tr>
<tr>
<td>Pre LAC Involvement</td>
<td>The more general Pre TCAT Involvement questionnaire was not allowing an in depth analysis of LAC involvement so this form was added to the back of the existing questionnaire in August 2016 with both Service Users and Carers</td>
</tr>
<tr>
<td>---------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Post TCAT Involvement</td>
<td>Used to document the experience of the person’s cancer journey since having the LAC involved.</td>
</tr>
<tr>
<td>Post LAC Involvement</td>
<td>As mentioned with above this form was added to gain a more in depth analysis of LAC involvement with both Service Users and Carers from August 2016</td>
</tr>
</tbody>
</table>

**How data was grouped and analysed**

Core data collection started when the referral routes opened in April 2016.

It was agreed that a full data set would comprise core data and all 4 completed questionnaires for analysing information about the person affected by cancer.

Initially it was anticipated data collection would end 28- Feb-2017, which would allow time to analyse the information and prepare a report before funding for the ICCC Project ended in July 2017. However due to unplanned staff absence the ability to gather the completed questionnaires was affected and the data collection end date had to be changed to 31-Dec-2016.

Had it been possible to continue collecting data until end of February 2017, there would have been 130 people affected by cancer which we could pull data from.

Due to the actual data collection end being December 2016 there were 104 people affected by cancer which we could pull data from.

In summary, the writer could not include the 130 for all aspects of analysis because without a full data set some information was not available. However, the core data was complete and it was agreed that inclusion of this data would provide a fuller picture of the demographics.

Diagram 4 details the number of completed data sets and those data sets that were incomplete for the cohort of 104.
Of the cohort of 104;

- **29** data sets were completed.
- **38** data sets were started but not completed due to frailty, death and other factors.
- **37** individuals were referred but were not seen by the project due to being hospitalised, or in long term care or those who did not want to be involved with the project.
- **67** people of the 104 cohort worked with the LACs and benefitted from their intervention over an 8 month time period.

Of those people who chose not to be part of the project, the main reason given was that they did not feel they required any further support at the time of contact or it was not something they were looking for.

It should be noted that the work of the LAC can extend over many weeks and months and circumstances can change dramatically for a person affected by cancer within this time span. It was therefore difficult to achieve completed data sets in all circumstances. A high proportion of the referrals into the project were for people with palliative care needs and whilst they may have been able to complete the pre TCAT questionnaire, many were too ill and frail to complete the post TCAT questionnaires as their condition had worsened.
At the beginning of the project, the use of the pre and post TCAT/LAC questionnaires were thought to be good tools to collect both quantitative and qualitative feedback to measure how effective the LAC approach was within the cancer care pathway. On reflection, the questionnaires were too lengthy and inappropriate for the population of the project. If a simpler tool had been used then more completed data could have been collected which would have offered a wider pool of results.

It also has to be noted that the ICCC project team found it challenging at times to get the evaluation questionnaires completed by Service Users because the forms created a barrier, at times, for the individual. The quote below depicts the feeling that some of our Service Users felt when given the questionnaires;

“I found filling in the questionnaire really distressing. I find those type of forms stressful to fill in at the best of times and at a time like this it brought everything home to me and it took me a few days to feel alright again afterwards”. (L. West Fife)

Analysis of the involvement of the Local Area Co-ordinator (LAC)

The data set questionnaires mainly focused on the experience of the individual on their cancer journey and then the impact of the LAC in the areas of control, support and confidence plus knowing where to seek help and being assisted to get required help.

The following findings and analysis will focus on the 29 completed data sets for people with cancer or who have had a cancer diagnosis and I then further on in the section move on to look at completed data sets for Carers of people with cancer.
Table 3 – Analysis of the 29 completed data sets

<table>
<thead>
<tr>
<th>Area analysed</th>
<th>Measurement scale of 1-10 score breakdown</th>
<th>Pre - TCAT Score</th>
<th>Post - TCAT Score</th>
<th>Difference in Pre and Post TCAT scores after LAC intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1-5</td>
<td>12 (41%)</td>
<td>0 (0%)</td>
<td>↑ 41%</td>
</tr>
<tr>
<td></td>
<td>6-10</td>
<td>17 (59%)</td>
<td>29 (100%)</td>
<td></td>
</tr>
<tr>
<td>Highest scores 8-10</td>
<td>9 (31%)</td>
<td>27 (93%)</td>
<td></td>
<td>↑ 62%</td>
</tr>
<tr>
<td>1. Confidence in managing own condition by self</td>
<td>1-5</td>
<td>10 (34%)</td>
<td>0 (0%)</td>
<td>↑ 34%</td>
</tr>
<tr>
<td></td>
<td>6-10</td>
<td>19 (66%)</td>
<td>29 (100%)</td>
<td></td>
</tr>
<tr>
<td>Highest scores 8-10</td>
<td>14 (48%)</td>
<td>29 (100%)</td>
<td></td>
<td>↑ 52%</td>
</tr>
<tr>
<td>2. Support received through cancer journey</td>
<td>1-5</td>
<td>21 (72%)</td>
<td>27 (93%)</td>
<td>↑ 21%</td>
</tr>
<tr>
<td></td>
<td>6-10</td>
<td>8 (28%)</td>
<td>2 (7%)</td>
<td></td>
</tr>
<tr>
<td>Highest scores 1-3</td>
<td>14 (48%)</td>
<td>27 (93%)</td>
<td></td>
<td>↑ 45%</td>
</tr>
<tr>
<td>3. Passed from person to person without support needed (*disagree =1-5, agree = 6-10)</td>
<td>1-5</td>
<td>10 (34%)</td>
<td>0 (0%)</td>
<td>↑ 34%</td>
</tr>
<tr>
<td></td>
<td>6-10</td>
<td>19 (66%)</td>
<td>29 (100%)</td>
<td></td>
</tr>
<tr>
<td>Highest scores 8-10</td>
<td>11 (38%)</td>
<td>26 (90%)</td>
<td></td>
<td>↑ 52%</td>
</tr>
<tr>
<td>4. Assisted to access services and help (disagree =1-5, agree = 6-10)</td>
<td>1-5</td>
<td>6 (21%)</td>
<td>0 (0%)</td>
<td>↑ 21%</td>
</tr>
<tr>
<td></td>
<td>6-10</td>
<td>22 (79%)</td>
<td>28 (100%)</td>
<td></td>
</tr>
<tr>
<td>Highest scores 8-10</td>
<td>15 (54%)</td>
<td>28 (100%)</td>
<td></td>
<td>↑ 46%</td>
</tr>
<tr>
<td>5. Feeling involved about decisions in care** (disagree = 1-5, agree = 6-10)</td>
<td>1-5</td>
<td>6 (21%)</td>
<td>0 (0%)</td>
<td>↑ 21%</td>
</tr>
<tr>
<td></td>
<td>6-10</td>
<td>22 (79%)</td>
<td>28 (100%)</td>
<td></td>
</tr>
<tr>
<td>Highest scores 8-10</td>
<td>15 (54%)</td>
<td>28 (100%)</td>
<td></td>
<td>↑ 46%</td>
</tr>
</tbody>
</table>

*The scoring was reversed and therefore the favourable results were from 1.

**The scoring was out of 28 as one person did not answer this question on both forms.
On table 3 the measurement scale is broken down into the lower scoring half 1-5, (1 being the lowest score and the higher scoring half 6-10, 10 being the highest score). The table also includes the scores achieved from 8-10 on the scale as most people scored the intervention of the LAC at this end of the scale.

The table of results (table 3) shows that people affected by cancer in Fife have had varied experiences within their cancer journey before TCAT, with results ranging across the measurement scale on the pre-TCAT questionnaire. Results in the post-TCAT column show that there has been an increase in every area analysed because of the LAC intervention.

Analysis of area 3. “Passed from person to person without support needed” has shown that post TCAT, two people have recorded a negative score. However on closer scrutiny it appears that this might be because of the change of scoring from 1 as the lowest score to 1 as the highest score. The rest of the results from the 2 questionnaires are very positive both numerically and written which indicates a misunderstanding of the scoring at this point.

“I was diagnosed with breast cancer last year. After treatment finished I felt very alone and vulnerable and didn’t like or recognise myself. I had lost all my hair and confidence...as we talked she made me realise I was not alone and was there for me.....it is very important to me as I wanted to help myself get back to everyday living....I am doing a lot better now, slowly getting my confidence back and take each day at a time....I'm in a better place right now thanks to the help of the TCAT Project”. (T. West Fife)

Other data collected from the cohort of 29 revealed that;
(all data has been rounded to 2 significant figures which accounts for discrepancy of %)

- **72%** felt that their needs were met in managing side effects/consequences of treatment. (**24%** did not want/need that support and **3%** did not know/couldn’t remember)
- **97%** felt their needs were met in knowing **where** to seek help. (**3%** didn’t know/couldn’t remember)
- **96%** felt their needs were met in understanding **who** to ask for help. (**3%** didn’t know/couldn’t remember)
- **86%** felt their needs were met in being made aware of support available for family members/carers. (**14%** did not want or need the support)
- **96%** felt their needs were in knowing what support services or groups they could use. (**3%** did not want or need the support)
Quantitative data has revealed that the majority of Service Users felt an improvement in their confidence, support, feeling helped by the LAC to access services and feel involved in decisions. These areas of improvement for individuals on their cancer journey, in particular their improvement in confidence, are the key outcomes of the LAC intervention and the key to self-management through a person centred, person led model of care.

Within the qualitative data from the completed questionnaires, including the LAC questionnaire, there is written evidence of the individuals feelings of how listened to, how informed and how much they valued the contact and “human” support that working with the LAC has provided them with. The main elements of this evidence are documented in 5 diagram below;

Diagram 5
The qualitative data gathered from the completed questionnaires revealed that the most valued elements of the LAC role was the accessible support and contact. This was further described as talking to someone who listened and had an understanding but who was also a direct point of contact to get in touch with whenever required which helped the person to not feel alone and feel reassured. The qualitative data also highlighted that people affected by cancer valued being visited at home; that they valued the information, knowledge and advice given but also the support to access services they found out about.

“The thing I valued most about the Phase 2 TCAT project was being visited at home and given the opportunity, on the initial visit, to reflect on my own situation”. (I. West Fife)

“This project has made a big difference to me, just being put into contact with organisations who called me and offered support has made me feel much less isolated”. (D. West Fife)

Carers’ involvement with the Local Area Co-ordinator

The focus for data collection for carers centred on evaluating the impact the ICCC Project had on their experience. The project recognised that carers could be supporting a dying or very sick spouse, or child, so they could be under considerable pressure and stress. To create forms for carers to complete, purely to allow the project to gather data, was deemed intrusive and unnecessary. The project therefore developed a pre and post carer questionnaire, (see table 4 below), which was felt to be as minimal as possible.

<table>
<thead>
<tr>
<th>Questionnaire Used</th>
<th>Rationale for use of specific Questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer Pre TCAT Involvement</td>
<td>Specific Carer questionnaire to capture the Carer’s experience caring for someone who has or has had cancer before LAC involvement</td>
</tr>
<tr>
<td>Carer Post TCAT Involvement</td>
<td>Used to document the Carer experience after LAC involvement</td>
</tr>
</tbody>
</table>
The project worked with 18 Carers in total and of those 18 there were 9 pre TCAT and 8 Post TCAT questionnaires completed. It is possible the low number of returns may be due to the lack of time carers had to fill out the forms because of their caring role.

Although this is not a large data set it does allow some measurement of the outcomes achieved by the LAC approach. Data analysis has demonstrated that overall 80% of Carers, within the data set, felt their confidence had increased after their involvement with the LAC, 80% also felt there was an increase in being listened to and 100% reported a significant improvement in feeling supported.

Within the qualitative data gathered from all the questionnaires completed by the Carers there is evidence of a marked difference in where Carers received their support before and after TCAT. Before TCAT Carers received support from family, friends and medical staff including their GP but after TCAT they found support in many different organisations and groups such as Maggie’s, Move more, Fife Carers Centre, Counsellors and Support in mind.

Diagram 6

“I’ve loved having you visit me at home to talk things through with me. Knowing that there was someone to turn to who would listen and help me has made a big difference and I’ve really appreciated it”. (M. Carer, West Fife)
“...you listened in a non-judgemental way, I could bounce things off you...you provided emotional and practical support”. (M. West Fife)

From both the quantitative and qualitative data gathered there is evidence that Carers have benefitted from LAC involvement as they have reported a significant increase in feeling supported and listened to but also in their confidence. This is further evidenced by the change in where support is received. A move away from family, friends and medical staff to local third sector organisations, services and groups.

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**Discussion**

1. Development of an integrated cancer care pathway into the community

A fundamental principle of the ICCC project was to work in partnership with both Phase one TCAT projects and the third sector but even with a good partnership structure in place it was a challenge for the ICCC project to set up and establish the pathway for support from a LAC and integrate this into the existing cancer care pathway. Extending the referral routes into the project was also a challenge but having achieved this, it proved successful over the operational period of the project.

As well as gathering data about the experience of people affected by cancer, questionnaires were also sent to professionals who had referred into the project. Although the return rate was low, the feedback that was received was very positive with all respondents reporting that they valued the LAC approach within the cancer care pathway.

So, what difference did the ICCC project make to people affected by cancer in Fife? To answer this question it is necessary to consider how the LAC approach differs to other
approaches within health and social care. The personal outcomes approach is well embedded within Fife Health and Social Care Partnership which means there is already an expectation that people affected by cancer will receive person centred care and support through their cancer journey. If the ICCC project did not exist, then people affected by cancer would still receive high quality personalised care but the pressure within the organisations to deliver with finite resources does lead to services being targeted to defined areas of need and therefore not all people get access to support when they need it.

The difference with the LAC approach is that it can be the bridge between services and between the clinical and non-clinical. By providing one person who can get alongside the person affected by cancer and empower them to identify what matters to them and what they need to do to make that better can make all the difference to people trying to navigate a complex service landscape.

“The most valuable support we have received so far has been being introduced to the TCAT Local Area Co-ordinator” (C. Central Fife)

In the first half of the operational phase of the project there were few referrals from nursing staff but this improved as trust in the project increased. Through a programme of meetings and briefings, clear links were established with the day hospice, groups of Cancer Nurse Specialists and Community Palliative Care Nurses

“The medical staff have done their best but nobody really offered me any support and I didn’t know whether there were any organisations that could help me”. (H. Central Fife)

Table 5 below shows where the 130 referrals of the original cohort originated from. The table highlights the large amount of referrals that have come from the Social Work Contact Centre and the other referral routes within NHS Fife.

Table 5

<table>
<thead>
<tr>
<th>Referral Route into Project</th>
<th>Number of referrals from 130 Cohort</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allied Health Professional - NHS</td>
<td>14 (11%)</td>
</tr>
<tr>
<td>Allied Health Professional – Social Care</td>
<td>5 (4%)</td>
</tr>
<tr>
<td>Cancer Nurse Specialist</td>
<td>4 (3%)</td>
</tr>
<tr>
<td>Community Palliative Care Nurse</td>
<td>22 (17%)</td>
</tr>
<tr>
<td>Contact Centre (Fife Council)</td>
<td>58  (45%)</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>GP</td>
<td>1  (1%)</td>
</tr>
<tr>
<td>Hospice</td>
<td>13 (10%)</td>
</tr>
<tr>
<td>Self-Referral</td>
<td>5  (4%)</td>
</tr>
<tr>
<td>Social Care (other Professionals)</td>
<td>3  (2%)</td>
</tr>
<tr>
<td>Third Sector</td>
<td>5  (4%)</td>
</tr>
</tbody>
</table>

Macmillan Survivorship Pathway

From the original 130 core data group, it was possible to plot which part of their cancer journey they were on by using the Macmillan Cancer Support Survivorship Pathway. This is depicted in diagram 3 below. (See appendix three for more information).

Diagram 3

In the diagram the timeline from rehabilitation occurs within 1 year of diagnosis. Early monitoring is up to 5 and 10 years from diagnosis (split into 2-5 years from diagnosis and 5-10 years from diagnosis). Late monitoring is beyond 10 years from diagnosis. Progressive illness means incurable disease, (not in the last year of life). End of life means in the last year of life. These definitions/timescales are attached to the scale.

Overall this scale demonstrates that referrals came from people across the whole journey; from those who had just been diagnosed to those at the end of life. This range of referrals provided the opportunity to evidence the impact that the LAC approach can have across the cancer journey and not just after treatment.
The Social Work Contact Centre advised that it is mainly people with cancer who have palliative care needs that are referred to them. The ICCC Project received a high number of referrals from the Social Work Contact Centre and the diagram above demonstrates this in relation to high numbers in the end of life category.

2. Testing the role of the Local Area Co-ordinator (LAC) in Community Cancer Care

LACs have traditionally worked with children and adults with learning disabilities. The ICCC project wanted to test this within cancer care.

The evidence confirms that the person centred, strength based approach which is highly regarded within learning disability models of care, was equally valued within cancer care. It was recognised that the LAC approach, which requires an investment of time to build rapport, led to people reporting feeling valued, connected and in control, not rushed or compromised by lack of time. The LACs also offered as many contacts as the person required and allowed the person affected by cancer time to follow through on their own plan of action to reach their goals. The ICCC project identified that this approach was necessary to empower people affected by cancer but it did lead to a build-up of referrals and therefore a waiting list. Whilst it was important for the ICCC project team to fully test the LAC approach realistically this may not be sustainable. The challenge is identifying how to hold onto the aspects of the intervention which people valued whilst managing to see people within a reasonable timescale.

Holistic Needs Assessment

One of the aims of ICCC project was to use the Macmillan Concerns Checklist Holistic Needs Assessment, (HNA). This a self-assessment which allows the person affected by cancer to identify their concerns about their cancer experience. From this a care plan is co-created.

The Macmillan HNA is used widely within health settings by health professionals but not with social work services.

Access to social work services within Fife Health and Social Care Partnership requires an assessment. If it had been agreed that the personal outcome support assessment be used by the LAC’s, (the assessment framework used within Adult and Older People Services), this would have required every person affected by cancer be referred to Social Work Services.

In striving to improve the cancer pathway and test the LAC approach, it is accepted that current pathways can lead to people being referred to services with waiting lists and
screening processes and this ultimately prevents the person at the centre from getting the right information or support at the right time.

Testing the HNA was an opportunity to test whether an assessment tool which is used in a clinical setting can also be used in a non-clinical setting and whether the LAC approach added value to the process by ensuring the outcomes/goals were not focused only on clinical outcomes.

The HNA assessment is completed and owned by the person affected by cancer and is the starting point of a strength based “what matters to me” conversation that acknowledges the effects of cancer on the person’s life.

The care plan is produced by the person and the LAC together with a focus supporting the person to recognise their strengths and how they can achieve goals which build their confidence and resilience to live with and beyond their cancer diagnosis.

As the person affected by cancer has ownership of the Holistic Needs Assessment and care plan, they are therefore in control of who they wish to share the documents with.

Use of the Concerns Checklist HNA and Care Plan within the ICCC project confirmed that this tool can be used successfully in a non-clinical setting and that with the added dimension of the LAC approach, people affected by cancer reported feeling empowered and more in control.

The 10 most common areas of concern

Diagram 7
The diagram above highlights that for those people who used the ICCC Project, the top 10 most common concerns raised were not medical. This strengthens the argument that a truly person centred and integrated pathway needs a mechanism which “bridges” the clinical and non-clinical. The ICCC Project believes this mechanism was the HNA and the intervention of a worker skilled in applying the principles which are found in the LAC approach.

Many professionals who referred to the project indicated that they did not have an extensive knowledge of the range of community services and assets and referred to the ICCC project for this reason. This does indicate that other professionals recognised that the ICCC Project was able to provide something important that within their day to day work, was not something they could fully provide. What the LAC’s had which they did not, was time to spend with the person affected by cancer to listen without having to apply criteria, (clinical or non-clinical) or keep the conversation focused to one area, (clinical or non-clinical).

“The LAC is very valuable in meeting the more “non-clinical” needs – these are often the things that exacerbate symptoms due to anxiety/worry/not knowing what is available. LACs help ensure patients have the information and more importantly the support to access services/resources.” (AHP, NHS Fife)

Follow up Work

It was recognised that follow up visits and phone calls offered extended support to the person affected by cancer and allowed them time to follow through on their plan of action to reach their goals. As the Holistic Needs Assessment is a “point in time”, self-assessment, people were encouraged to complete it a second time near the end of the LAC involvement. This enabled the person affected by cancer to revisit any remaining concerns or issues and also an opportunity to compare how things felt for them at the start of their process and the end.

From the cohort of 104 Service Users; there were 484 concerns raised from the first Holistic Needs Assessment. At the point of the second Holistic Needs Assessment and follow up work the number of concerns reduced to 185; a 62% reduction in concerns raised; which is depicted in diagram 8.
Analysis of the 185 concerns raised in the follow up sessions found they were mainly physical in nature which is understandable when looking at the results of the Survivorship Scale which showed that people affected by cancer within the cohort are concentrated within the diagnosis, rehabilitation, early diagnosis and end of life stages. The analysis of the concerns raised highlighted that most of the other concerns in the other areas of the Holistic Needs Assessment, such as those depicted in diagram 7 where resolved fully or were being worked on.

**Self-Management**

One of the key aims of the national TCAT programme is to help people play a more active role in managing their own care; supporting and encouraging self-management skills.

The project findings have evidenced that people affected by cancer have identified an improvement in their confidence and feeling involved in decisions and the approach of the LAC was a key element.

“Being involved with the TCAT project has been really good because it let me know about other groups and organisations who were there to support me and I wouldn’t have done anything on my own without that help”. (S. West Fife)

The LACs acquired a robust knowledge of support services in the community and helped people affected by cancer consider whether those services could compliment their own resources and increase their feelings of being in control. The LAC’s consequently helped people affected by cancer refer to a large range of groups, organisations and services within their local community and wider.
“The best thing has been the way you’ve linked everything together, that you came out and said things would happen and they did, it’s been fantastic and that’s never happened to me before”. (C. North East Fife)

From the data gathered for the project, there is evidence that people affected by cancer feel more supported and feel they have more access to services which has enhanced their ability to take more control within their cancer journey.

The project evaluation has captured information on engagement with community services/groups. From the 104 cohort of people affected by cancer, 67 engaged with the ICCC service and accessed services and supports in their local community as did all 18 Carers. Adding both the person affected by cancer and Carer figures together means that 85 people accessed community services.

From the data collected on the LAC follow up work of the 104 cohort, 49 out of the 67 (73%) fully engaged with community support and information sources and have moved forward into managing their condition and helping them deal with the physical, emotional and financial impact of cancer treatment as well as enjoying hobbies and past times within their communities.

Many of these groups, organisations and services are depicted in the word cloud below;
“At the point when I was put in touch with the TCAT Project, I didn’t know which way to turn. I knew that I needed help because I was really struggling but I didn’t know who could help me or how to get that help. I spoke to the Macmillan Welfare Adviser and she told me about TCAT and put me in touch with the project. For me personally, being involved with the project has been marvellous. Everything moved so quickly and I was put in touch with organisations who could help me. I’ve been attending an exercise class at Move More and a computer class locally as a result of being involved with TCAT.” (E. West Fife)

People living in outlying, rural areas of Fife reported very limited access to centralised services and supports due to poor transport links. This has been a challenge to the ICCC Project.

Within Fife there is an online search tool called “On Your Doorstep” for sourcing community groups, organisations, information or support which has allowed the LAC to source invaluable information on local community groups and services. Work has begun to input the data bank of known groups and organisations that the ICCC LACs have compiled around cancer care onto the “One Your Doorstep” websites to make this accessible to more people to aid self-management.

Meeting Health and Wellbeing Outcomes through the Role of the LAC

The following case study illustrates how the ICCC Project and the LAC approach is consistent with the Health and Wellbeing Outcomes.

**R.R and J.R. and their Cancer Journey with ICCC Project**

- R.R. was referred to the TCAT service from the Social Work Contact Centre. She had been diagnosed with breast cancer but had a previous diagnosis for breast cancer over 10 years ago.

- R.R. lives centrally in a large town with her 19 year old son (JR) and is experiencing physical difficulties due to the side effects of her cancer treatment.

- R.R. has been feeling unsupported and had difficulty accessing local support services. What really matters to RR is how her son is coping in his caring role and how he is managing to cope with his studies at college.
<table>
<thead>
<tr>
<th>Concerns Highlighted</th>
<th>Care Plan – Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical Concerns</strong></td>
<td>R.R. was encouraged to speak to the CNS and GP for advice about specific physical concerns. Information booklets about fatigue and management of symptoms of cancer treatments were sourced and provided.</td>
</tr>
<tr>
<td>R.R. listed 11 physical concerns including issues with pain, fatigue, sleep and appetite</td>
<td></td>
</tr>
<tr>
<td><strong>Practical Concerns</strong></td>
<td>R.R. wanted to cook for her son but was functionally unable therefore to reach her goal she agreed to a referral to the Social Work Occupational Therapy Service for a functional assessment and to a referral to the Marie Curie befrienders to work together on meal preparation. The LAC sourced information about wheelchair travel in the airport and abroad plus information about travel insurance to assist R.R. to start planning the trip with her mum</td>
</tr>
<tr>
<td>R.R.’s practical concerns surrounded caring for her son, insurance and travel as she wished to go on holiday with her mum and she was having issues cooking</td>
<td></td>
</tr>
<tr>
<td><strong>Family Concerns</strong></td>
<td>R.R.’s son requested a Carers Referral to work with the LAC</td>
</tr>
<tr>
<td>R.R. reported concerns about how her son was coping with her illness and about how this affected other relatives and friends</td>
<td>R.R. agreed to a referral to Fife Community Listening Service referral to talk through family concerns. The LAC also provided information booklets on talking about cancer to family and friends.</td>
</tr>
<tr>
<td><strong>Emotional concerns</strong></td>
<td>This is another area of work the Community Listening Service worked through with R.R. and she was also supported to go on to speak to her GP to explain her emotional concerns and get advice about whether there was any treatment she could benefit from.</td>
</tr>
<tr>
<td>R.R. reported issues of sadness/depression and of loss of interest in activities</td>
<td></td>
</tr>
<tr>
<td><strong>Lifestyle Concerns</strong></td>
<td>The Marie Curie Befriender accompanied R.R. on walks with and her dog which gave her confidence. R.R. enjoyed being able to do this.</td>
</tr>
</tbody>
</table>
JR is the 19 year old son of RR and studies full time at college. He lives at home with his mum and is her main carer. He tends to assist mainly in household tasks. JR reported that he does get some support from his sister via the phone as she does not live locally. JR self-referred to the ICCC LAC once he knew that carers could also access the service. He explained to the LAC that he was looking for advice and help as he did not know where to access support locally. JR expressed the anxiety that he was experiencing in his caring role and was planning to give up college to relieve some of his stress.

<table>
<thead>
<tr>
<th>Concerns Highlighted</th>
<th>Care Plan – Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety and stress</td>
<td>The LAC referred JR to a teenage and young person psychologist for counselling to allow him to discuss his situation and find ways to cope.</td>
</tr>
<tr>
<td>College Studies</td>
<td>The LAC negotiated a meeting with the curriculum head at College who then offered solutions to JR to help him cope with his studies along with his caring responsibilities. He is now able to work more from home. He emails his assignments and course work to his course lead which has enabled JR to cope with his studies and caring role. As a result of this intervention JR has decided to stay at college.</td>
</tr>
</tbody>
</table>

As a result of the outcomes of the LAC intervention for JR he has reported feeling more supported and now feels he can carry on with his studies. As a further outcome, RR feels that her concern surrounding her son’s ability to cope has reduced which has improved her own health and wellbeing.

Relating this to the 9 national health and wellbeing outcomes of integration (appendix one) it is clear that LAC approach complements these. Looking at the case study for RR it can be clearly seen the correlation to the nine health and wellbeing outcomes around the journey towards self-management and independence. RR has been treated with dignity within an inclusive service which has helped to improve her quality of life. Also, the same person centred approach was taken with RR’s main carer, her son. He was treated with the same care and respect and was able to improve his own health and wellbeing outcomes with input from the LAC.
3. Development of the Cancer Champions network within TCAT

Currently there are 29 Cancer Champions in the network (8 from Adult Services, Social Work; 3 from Occupational Therapy, Social Work; 3 from Adult Services, Adult Resources; 6 from Older People Service, Social Work; 1 from the independent sector; 8 from the third sector).

The Cancer Champion Network is an integral element of the ICCC project, set up to spread and share acquired knowledge within teams, identify gaps in service and improve signposting. It was anticipated that this practical networking approach would enhance the impact of the phase 2 project by raising awareness about cancer and the experiences of people affected by cancer.

The Cancer Champion Network evolved over the life of the project. Initially the network was limited to people employed within Adult Services, (where the ICCC Project lead was). The rationale for this being that we wanted to get the network established with a smaller group before we widened out to other partners within health and the third sector. The intention was that once the network was established the project would look for a host out with Adult Services and ideally out with the Fife Health and Social Care Partnership.

Fife Voluntary Action agreed to host the Cancer Champion Network to assist the transition away from the Fife Health and Social Care Partnership with the end goal of having an independent, integrated group in Fife for sharing and learning, sitting confidently within the third sector.

4. Work effectively within an integrated framework to enhance the success and sustainability of the TCAT project (Aims 4 and 5 combined)

The TCAT programme preference was that all phase two local authority projects would link with the respective phase one NHS project, (if one existed). The ICCC Project was able to achieve this by linking with both Fife NHS Projects.

This integrated approach between the Fife projects promoted shared understanding, shared learning and wider partnership working with our third and independent sector partners.

The phase one NHS Fife skin project and the phase 1 NHS lung project initially had separate steering groups. The ICCC Project initiated a shared steering group for all 3 projects. This joint steering group had representation from NHS Fife TCAT projects, Fife Health and Social Care Partnership TCAT project, Fife Council, patient representation, third sector, Macmillan Cancer Support and South East Scotland Cancer Network, (SCAN).
Both of the phase one NHS Fife projects had operational groups as did the ICCC project, (phase 2 H&SCP) and each project was represented on each operational group.

A joint newsletter was developed which allowed for joint communication strategy of all 3 projects.

The development of the Fife TCAT Patient/Carer Reference Group which involved Patient and Carer representatives from each TCAT project ensured that

Educational events and presentations for Macmillan Cancer Support, SCAN and Melanoma workshops were jointly arranged by and for NHS Fife, Fife Council and Fife Health and Social Care Partnership staff

The ICCC Project worked jointly with Maggie’s Centre, Fife in supporting the peer to peer sessions.

The Cancer Champion network was established to bring people with an interest in cancer together from all sectors (including people affected by cancer and their carers). This enhances integrated and joint working by creating opportunities for making relationships and networking.

The ICCC Project worked jointly with Move more Fife, Fife Council.

There was also close working with Citizens Advice, Rights office, Fife (CARF).

Partnership working with Primary Care services helped to develop the referral routes and extend community networking.

The ICCC project worked closely with Victoria Hospice to support the discharge of day patients back into the community

An approach was also made to Fife Forum who employ LAC’s, to consider how their LAC’s could support people with cancer by replicating the project’s approach and also to discuss the benefits of developing a local LAC network.

The commitment to partnership working by all 3 TCAT projects enabled sharing of knowledge, improved understanding of each other’s service/profession and shared goal to contribute to a cancer strategy in Fife that and makes a real difference to the experience of for people affected by cancer in Fife. Working together at a strategic and operational level established relationships and strengthened the commitment to continue developing integrated working for cancer services in Fife.

Further detail of specific partnership working with both of the NHS phase one TCAT projects is outlined below;
Melanoma TCAT Phase One Project

The ICCC project worked closely with staff from the Melanoma project to develop a local resource information bank. This was started by one of the specialist dermatology link nurses and then handed over to the ICCC project to further develop with information on resources in the local community. The LAC’s link with staff from the Melanoma project at regular intervals to update on progress of the information bank and share any new information to update it. Work is underway to start including this data bank of local information onto the Fife “On Your Doorstep” information website and then onto the national NHS Inform website to widen access as much as possible.

The Melanoma project delivered workshops to their patients and the LAC’s from the ICCC project participated in those workshops. They delivered sessions about their approach and the support they can offer. Feedback was very positive. The LAC’s have supported 5 workshops to date and have another 3 planned for 2107.

Lung TCAT Phase One Project

The ICCC project and the lung project both participated in a trial of a shared NHS/H&SCP portal. This provided data for the “proof of concept”.

Effectively each project was able to access agreed information from their respective information systems. This resulted in a reduction of duplication of some aspects of work. As the portal was a test site there were a few issues but generally it was felt by both projects that the shared portal would be of benefit to patient care.

Fife TCAT Patient/Carer Reference Group

The ICCC project worked closely with Simon Malzer from Alliance Scotland who is the User Involvement Manager for the TCAT programme and oversees the Patient Experience Panel.

The Fife TCAT Patient/Carer Reference Group was developed to offer patient/carer representatives a more meaningful, proactive role within the TCAT project. As there was a referral route from each phase 1 project into the phase 2 project it was agreed that the phase 2 project would co-ordinate the group along with Simon.

The group wanted to gather feedback from people who were going through their cancer journey and were experiencing the improved cancer pathway through TCAT. The information gathered was then to be fed back to the projects to help inform and enhance future service development. Initially the plan was to organise focus groups but numbers were small so a peer to peer meeting scheme was established. The peer meetings were programmed to take place in Maggie’s Centre, Kirkcaldy or other community venues which are more local to the individual to offer some flexibility. The Local Area Co-ordinator organised and supported the meetings and with consent, recorded the positive and negative aspects of the individual’s cancer journey as well as suggestions to improve services. The
peer model also offered an option of home visits for people who were unable to leave their home.

A number of peer meetings were undertaken by the patient representative from the Melanoma project with one of the LACs. The findings from the sessions were fed back to the Melanoma project and affected some changes within the delivery of the care pathway for the Melanoma project which validates the effectiveness of the peer meetings. Appendix Five outlines the working Peer to Peer Model established through the TCAT Patient/Carer Representative Reference Group.

Work is continuing to look at ways of sustaining the valued work of the TCAT Patient/Carer Reference Group. Maggie’s Centre staff already have a connection to the group and may be able to offer more support in the future. In the meantime the Melanoma workshop programme is set to continue and therefore more opportunities will be available to offer peer meetings to patients who would want to share their cancer experience.

Limitations, Challenges and Sustainability of ICCC TCAT Project

A strength of the ICCC project has been its responsiveness to emerging opportunities or gaps in services. However this flexibility did create problems in relation to the data gathering, (required for the wider, external Napier Evaluation). For example, the initial questionnaires was revised to improve the usability of the form. Also, the LAC questionnaire was an additional form added to get more in depth information on the LAC approach when it became apparent that there was not enough detailed information being gathered. On reflection, these changes helped the collection of qualitative data but had an impact of limiting the amount of in depth quantitative data gathered.

The other main issue surrounding incomplete data sets was the decision to have open up referral routes for any person affected by any cancer type at any point in their cancer journey. As explained earlier, many people were unable to complete a 2nd questionnaire,
(designed to measure outcomes and what changed from start of LAC involvement to end), or they died.

Whilst this has been a challenge, there is evidence that people even at the end of their life, did benefit from the intervention of the LAC and any data we have been able to gather has been of huge benefit to the project. It has allowed the project to evidence the value of the LAC approach at all stages of the cancer journey. Additionally it has provided the LAC’s with an opportunity to gain experience in working with people aged 17, the youngest to be referred, all the way to 97 which is the oldest person to have contact with the LAC. This experience has also been gained in supporting people with different cancer types at different stages of their cancer journey.

The size of the project was a limiting factor. The ICCC project comprised the full time Project Manager and one full time and one part time LAC. The LACs cover the whole of Fife which is a very large geographical area with many outlining rural villages. As noted earlier there was a waiting list and a period of unplanned absence from the part time LAC had a further impact on this.

As the Improving Cancer Journey project starts up and progresses, the profile of cancer will continue to be raised at a strategic level within the Fife Health and Social Care Partnership and the continuation of the development of cancer services, the cancer care pathway and partnership working in Fife.

The Cancer Champion Network. The vision for the network is for it to be hosted within the third sector. The Improving Cancer Journey project will be able to progress this vision.

There is also an opportunity with this additional funding for Improving Cancer Journey, to build on the learning from this ICCC project regarding the value of the LAC approach.
Conclusion and Recommendations

There is evidence that the overall and individual project aims have been met.

There is evidence within the findings that the LAC approach has supported people affected by cancer to feel increased confidence as well as feeling supported and listened to. There is evidence that the LAC approach offers people the time and space to find the information and support which is right for them and this is valued by people affected by cancer and has a place within the Cancer Care Pathway.

“The TCAT project has helped me recognise what I want in life and has made me realise what is important to me”. (C. Central Fife)

The Cancer Champion Network is continuing to develop into an integrated network of sharing and learning with a clear aim of improving services for People Affected by Cancer. The group are working towards a sustainable future through the hosting skills of Fife Voluntary Action.

The integrated framework of the Fife TCAT projects has allowed a collective approach to raising the profile of cancer and has developed a good foundation for the continual development of the cancer strategy in Fife.

Recommendations, based on the outcomes from the ICCC project, are as follows;

1. The ICJ Project will build on the successful outcomes and learning from testing the role of the LAC within the TCAT ICCC project. Therefore the ICJ service will include LAC’s and the principles of the LAC approach.

2. The transition from the TCAT ICCC project to the ICJ service will need to be as seamless as possible to reduce the risk of disruption to the established pathway.

3. Development of an effective communication strategy is crucial to achieve this.

4. That the ICJ service continue the LAC Carer work as this has been a successful element of the TCAT ICCC project and the level of information and supported navigation, specifically for Carers whose family member has cancer, has been valued.

5. That the ICJ identify meeting points/clinics in each locality of Fife, or different localities across Fife. This will allow the LAC’s to see more people at a central, easily accessed point, (a benefit for people affected by cancer who cannot travel long distances) and thereby increase the amount of people the LAC’s can see. Home
visits will still be necessary for some Service Users but this can be worked out on a case by case basis.

6. Introduce more follow up phone contacts to increase capacity of the LAC role. This approach will need be monitored to ensure that it does not detrimentally impact the highly valued person centred approach, which has been evidenced in testing the LAC role with people affected by cancer.

7. People affected by cancer were able to self-refer ICCC Project. Otherwise they had to give consent for a third party to refer on their behalf, (ie clinical nurse specialist, allied health professionals). This is described as an “opt in” referral system. The preferred option would be an “opt out” referral systems and it is recognised that this will be explored as part of ICI. It is recommended to continue with the current “opt in” referral route until any further enhancements to referral pathways are agreed.

8. Work has begun to add the local knowledge of community cancer services into Fife’s local information website, “On Your Doorstep”. This will extend to include this information on the national NHS Inform website and directory to ensure that the wider population and networks can access this information. However, further expansion of the LAC role into community capacity building will further increase knowledge of services and assets within communities and identify gaps that might exist within different localities.

9. Continuation and development of the work achieved through the Fife TCAT Patient/Carer Reference Group. While this group will no longer exist as TCAT phases 1 and 2 come to an end in Fife, it is recommended that the group’s legacy helps shape the inclusion of “User Representative” involvement in the ICI project.

10. Continued involvement in the Cancer Champion Network, which will sit within the third sector, to promote sharing and learning in Fife within an integrated Cancer network.

11. Continuation of integrated partnership working at a strategic and operational level with a commitment from all parties to work towards permanent long term vision for the transformation and integration of Cancer services in Fife.
Appendices

Appendix One

National Health and Social Care Outcomes;

**Outcome 1** - People are able to look after and improve their own health and wellbeing and live in good health for longer.

**Outcome 2** - People, including those with disabilities or long term conditions or who are frail, are able to live, as far as reasonably practicable, independently and at home or in a homely setting in their community.

**Outcome 3** - People, who use health and social care services, have positive experiences of those services and have their dignity respected.

**Outcome 4** - Health and social care services are centred on helping to maintain or improve the quality of life of people who use those services.

**Outcome 5** - Health and social care services contribute to reducing health inequalities.

**Outcome 6** - People, who provide unpaid care, are supported to look after their own health and wellbeing; this includes the reduction of any negative impact of their caring role on their own health and wellbeing.

**Outcome 7** - People, using health and social care services, are safe from harm.

**Outcome 8** - People, who work in health and social care services, feel engaged with the work they do and are supported to continuously improve the information, support, care and treatment they provide.

**Outcome 9** - Resources are used effectively in the provision of health and social care.
Appendix two – HNA and Care plan

Identifying your concerns

Discussed by:
Date:
Designation:
Contact details:

This self-assessment is optional, however it will help us understand the concerns and feelings you have. It will also help us identify any information and support you may need in the future.

If any of the problems below have caused you concern in the past week and if you wish to discuss them with a health care professional, please tick the box. Leave the box blank if it doesn't apply to you or you don't want to discuss it now.

I have questions about my diagnosis/treatment that I would like to discuss.

Physical concerns
- Breathing difficulties
- Passing urine
- Constipation
- Diarrhoea
- Eating or appetite
- Indigestion
- Sore or dry mouth
- Headache or vomiting
- Sleep problems/nightmares
- Tired/exhausted or feeling like you have a fever
- Swollen tumour or limb
- High temperature or fever
- Getting around (walking)
- Tiring in hands/legs
- Pain
- Hot flushes/sweat
- Dry, itchy or sore skin
- Wound care after surgery
- Memory or concentration
- Taste/lack of taste
- Hearing
- Speech problems
- My appearance
- Sexuality
- Unplanned changes in weight

Practical concerns
- Caring responsibilities
- Work and education
- Money or housing
- Insurance and travel
- Transport or parking
- Contact/communication with NHS staff
- Housework or shopping
- Washing and dressing
- Preparing meals/shopping

Family/relationship concerns
- Partner
- Children
- Other relatives/friends

Emotional concerns
- Difficulty making plans
- Loss of interest/activities
- Unable to express feelings
- Anger or frustration
- Guilt
- Hopelessness
- Loneliness or isolation
- Sadness or depression
- Worry, fear or anxiety

Spiritual or religious concerns
- Loss of faith or other
- Spiritual concern
- Loss of meaning or purpose of life
- Not being at peace with
- Feeling regret about the past

Lifestyle or information needs
- Support groups
- Complementary therapies
- Diet and nutrition
- Exercise and activity
- Smoking
- Alcohol or drugs
- Sun protection
- Hobbies
- Other

Please mark the scale to show the overall level of concern you've felt over the past week.

You may also wish to score the concerns you have ticked from 1 to 10.

1  2  3  4  5  6  7  8  9  10
Lowest  Highest

WE ARE MACMILLAN CANCER SUPPORT

DH Department of Health

NHS Improvement

This activity is part of the NICE Cancer in the African Caribbean Quality Standards Initiative. National Institute for Health and Clinical Excellence (NICE) guidance.
Care plan

Completed by: 
Date: 
Designation: 
Contact details: 

Patient’s name or label

Level 1: Score 0–3 Mild concerns
Discuss sources of concern with the patient, include information, contact details and monitor.

Level 2: Score 4–6 Moderate concerns
As above for level 1 and provide information and discuss with a colleague if necessary and signpost to support. Use second level assessment tool if appropriate eg NADS.

Level 3: Score 7–10 Significant concerns
As above in Level 1 and 2 and use second level assessment tool if appropriate eg NADS and refer to specialist services if required.

Overall score on the scale:

<table>
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<tr>
<th>Main concerns</th>
<th>Score</th>
<th>Description of concern</th>
<th>Plan of action</th>
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Copies sent to: 
Next review due: 

[Logos of Macmillan Cancer Support, Department of Health, and NHS Improvement]
Appendix Three – Macmillan Survivorship Pathway

- Diagnosis and Treatment = newly diagnosed
- Rehabilitation = the first year
- Early Monitoring = Up to 5 and 10 years from diagnosis (split into 2 -5 years and then 5-10 years)
- Later Monitoring = Beyond 10 years from diagnosis
- Progressive Illness = Incurable disease but not in last year of life
- End of Life = End of life care in last year
Appendix Four – Example of a Project Questionnaire

PRE - TCAT: Patient Views and Experiences

Thank you for being part of the Integrated Community Cancer Support-Transforming Care After Treatment Project (ICCC-TCAT Project).

We are interested in finding out more about what has happened to you on your cancer journey before the ICCC-TCAT project has been involved.

By giving us your feedback we can understand your experiences better and identify how we can improve our service.

It will only take a few minutes to complete. The information you provide is anonymous and will be treated confidentially.

1. Are you male or female?

☐ Male
☐ Female

2. What type of cancer were you treated for? ___________________(please write in)

3. Up until this point in your cancer journey how confident were you that you could manage your condition by yourself? Here “managing” means understanding ways to cope and knowing where to seek help if needed.

Not at all confident

Very confident

1 2 3 4 5 6 7 8 9 10
4. **Overall**, how would you rate the support you have received through your cancer journey before the ICCC-TCAT project became involved? Here ‘support’ includes any appointments, advice you have been given, information, being referred to or signposted to people or organisations that could help you.

<table>
<thead>
<tr>
<th>Very Poor Support</th>
<th>Very Good Support</th>
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<tr>
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<td>😊</td>
</tr>
</tbody>
</table>

1 2 3 4 5 6 7 8 9 10

5. **Before** ICCC-TCAT project became involved, what has been the most **valuable support** you have received?

_____________________________________________________________________

___________________________________________

6. **Up until this point in your cancer journey**, do you have any ideas /comments about how the support you received at this point in your cancer journey could be improved?

_____________________________________________________________________

___________________________________________

7. **Up until this point on your cancer journey**, what extent were your needs met in relation to the following?

a) Managing side effects/consequences of treatment? (Tick one box only)

- [ ] Needs were met completely
- [ ] To some extent
- [ ] Not at all
- [ ] I did not want/need this type of support
b) Knowing **where** to seek help if you need it? (Tick one box only)

☐ Needs were met completely

☐ To some extent

☐ Not at all

☐ I did not want/need this type of support

☐ Don’t know/can’t remember

c) Understanding **who** to ask for help if you need it? (Tick one box only)

☐ Needs were met completely

☐ To some extent

☐ Not at all

☐ I did not want/need this type of support

☐ Don’t know/can’t remember

d) Awareness of support available to your family/carers? (Tick one box only)

☐ Needs were met completely

☐ To some extent

☐ Not at all

☐ I did not want/need this type of support

☐ Don’t know/can’t remember
e) Knowing about other support services or groups you could use? (Tick one box only)

☐ Needs were met completely
☐ To some extent
☐ Not at all
☐ I did not want/need this type of support
☐ Don’t know/can’t remember

8. **Up until this point in your cancer journey**, to what extent do you agree with the following statements?

a) I was passed around from person to person without getting the support I needed

Strongly DISAGREE                       Strongly AGREE

1  2  3  4  5  6  7  8  9  10

b) I was assisted to get other services and help, and to put everything together.

Strongly DISAGREE                       Strongly AGREE

1  2  3  4  5  6  7  8  9  10
c) I have been involved in decisions about my care.

Strongly DISAGREE  Strongly AGREE

1  2  3  4  5  6  7  8  9  10

9. Up until this point in your cancer journey, have you used/visited any organisations, services or individuals for information, advice or support?

☐ Yes
☐ No

10. If yes, please list here the agencies, services and individuals you have received support from.

___________________________________________________________________________
___________________________________________________________________________

Date completed: __________________________    Thank you

<table>
<thead>
<tr>
<th>Project Number</th>
<th>Patient Number</th>
</tr>
</thead>
</table>
Appendix Five – Peer to Peer Model

Peer Support Sessions Process

Client wishing to share patient experience identified through work with LAC or at Melanoma Workshop

Suitable date, time and venue identified by LAC in conjunction with Patient Rep and PABC

LAC facilitates the session by taking notes and supporting Patient Representative

Session held where Patient Rep shares their experience and invites PABC to do the same

Individual issues and common themes from sessions discussed at TCAT Patient/Carer Representative Reference Group

Findings fed back directly to Consultant or through TCAT Project to relevant department/service within NHS or Local Authority

Alternative Feedback route through the Patient Relations Team if required
References

1. Cancer Research UK Cancer Statistics:  
   http://www.cancerresearchuk.org/health-professional/cancer-statistics/risk/lifetime-risk
   http://ihub.scot/media/1130/fife.pdf
8. The Public Bodies (Joint Working) (Scotland) Act 2014