Transforming Care After Treatment (TCAT)

NHS Fife Melanoma Evaluation Report

September 2014 – August 2016
FOREWORD

It is a pleasure to introduce this evaluation report which describes the important work of this project to improve the care and experience of patients in Fife who have been diagnosed with melanoma skin cancer. This is an example of the clinical excellence that many teams strive to deliver everyday for our patients. It builds on the national policy aim of delivering person-centred care and Transforming Care After Treatment, and as you will read has shown the value of the partnership with patients to understand their experience to help redesign the patient pathway.

The project involved the wider multi-disciplinary team that helps deliver holistic care based on the patient's individual circumstances and demonstrates the value of involving patients in making sure treatment and follow up is personalised to them. The positive development of peer to peer review sessions is also welcome. The development of rapid access back into the service will I am sure give both patients and their GPs confidence to manage their ongoing care and to understand what would be a worrying change to alert the specialist service that review is required.

The project has also demonstrated the value of integrated working across the health service, Fife Council and the third sector and brings to life the aims of better integration of health and social care to improve patient experience.

I welcome the aims of the next phases of this project in terms of prevention and detecting cancer early and look forward to reading the outcome of this work in the future. It is also good that the Fife experience can be shared to support wider transformation of care for patients with melanoma skin cancer across Scotland and further afield.

I commend this report to all those interested in Transforming Care after Treatment of cancer. My thanks go to Dr Mowbray for her leadership, the teams and the patients involved for this great work.

Dr Frances Elliot
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Executive summary

NHS Fife melanoma transforming care after treatment (TCAT) project

Acknowledgement

The NHS Fife skin cancer support team would like to thank all those who have contributed to this project and the development of our service. The participation of patients and their families in this project, and their willingness to provide feedback at all stages in the process, has been invaluable. A highlight of this project has been the integration of colleagues working across primary care, secondary care, social care and the third sector. We thank all these colleagues for their enthusiasm and dedication in making this project a success. Particular thanks go to our patient representative, Ian Stone. Ian has dedicated many hours of his time to this project and continues to develop his role in supporting skin cancer patients, evaluating our service, and encouraging skin cancer prevention. Finally, we thank Macmillan Cancer Support for supporting this project both financially and with their expertise.

Background

- Malignant melanoma of the skin is the 5th commonest cancer in Scotland.
- Melanoma has increased in incidence in Scotland over 50% in the last 10 years and continues to do so.
- The annual increase in dermatology referrals impacts on the capacity of the skin tumour clinic to meet the holistic needs of the melanoma skin cancer patient.
- In 2009 NHS Fife developed two ‘skin cancer link nurses’ (SCLN) at each of the two hospital sites. The SCLN is a dermatology nurse with additional education and experiential learning in skin cancer. It soon became realised that the role of the SCLN was invaluable to both patients and clinicians in providing local support for melanoma patients. However, her role was unfunded and additional to other timetabled nursing care.

Pre TCAT

Active treatment – the majority of melanoma patients have their primary melanoma excised in the department of dermatology.

Definitive treatment – following active treatment the majority will have their definitive treatment in the department of plastic surgery. They will have a wide local excision (WLE) with a proportion also having a sentinel lymph node biopsy (SLNB).

Follow-up takes place in the department of dermatology. All consultant follow-up clinic appointments are of 10 minutes duration. The length of follow-up is determined by the Breslow thickness (prognostic indicator) of the melanoma. Follow-up is either 3 monthly for 1 year or 3 monthly for 3 years, thereafter 6 monthly for a further 2 years.

- This model of conventional follow up clinics did not address a patient’s holistic and individual needs. A 10 minute consultant consultation did not tolerate for discussion about what mattered to the patient and the support available.
- The pre-TCAT model did not allow rapid patient-led access back into secondary care once a patient had been discharged.
We wished to build on the developments that had been made between 2009-2013 with the SCLN and develop a new way of managing follow-up with a multi-partnership approach to maximize success.

**Macmillan TCAT aims**

- To enable people affected by cancer to play a more active role in managing their own care.
- To provide services which are more tailored to the needs and preferences of people affected by cancer.
- To give people affected by cancer more support in dealing with the physical, emotional and financial consequences of cancer treatment.
- To improve integration between different service providers and provide more care locally.

**NHS Fife Melanoma TCAT project aims**

To develop the melanoma patient pathway in line with the aims of the Macmillan transforming care after treatment programme.

The specific aims of this project will be:

1) **To understand the experience of NHS Fife melanoma patients, improve the patient pathway, and make changes to the service where appropriate** - this understanding was gained by holding a patient focus group to discuss the existing service and aims of the project.

2) **Development of dermatology skin cancer link nurse clinic (dSCLN)**
   a. 2.1 - Development of a dSCLN clinic should make more efficient use of Consultant and nurse time.
   b. 2.2 - Training undertaken to enable dSCLN to achieve the TCAT aims with regard to Holistic Needs Assessments (HNA) and SCLN clinics.
   c. 2.3 - Holistic Needs Assessment (HNA):
      Introduce the use of the HNA during the 30 minute appointment with dSCLN.
   d. 2.4 Personal plan:

3) **Introduction of an efficient system for rapid access back into secondary care.**

4) **Electronic end of Treatment Summary (EOT) to be created for all patients and:**
   i) Sent to GP at the end of active treatment
   ii) Sent to GP on discharge from dermatology to primary care.

5) **Patient “opt in” to copy of clinic letters**
   a. This allows for enhanced communication between patient and clinicians and will enable patient empowerment.
6) **Melanoma Workshop – patient self-management**
   a. The workshop programme to be developed using feedback from the patient focus group. To show integration of all service providers (dermatology, plastic surgery, Macmillan, Fife social care, Fife council, Maggie’s Fife). To deliver a programme which enables psychosocial support and introduces the patient to the variety of service providers available to them.

7) **Development of plastic surgery skin cancer link nurse (pSCLN)**
   This will follow the model of the dermatology SCLN. The role of a plastic surgery skin cancer link nurse will be developed to ensure a more detailed understanding of melanoma skin cancer. This will enable us to have a person who is a point of contact and support through the plastic surgery pathway. This role will be available to provide enhanced support to the more complex patients and to develop multi professional clinics and enhance support within the team. This development will enable effective communication between dermatology and plastic surgery.

At the commencement of the TCAT project the plastic surgery nursing staff did not have the capacity to develop the role of pSCLN. As of September 2016 this role is being developed. **This aspect of our project will now be considered as a ‘stand alone’ phase III TCAT project.**
Outcomes – the new model of melanoma cancer care in Fife

A patient focus group was held at the beginning of the project. This has provided invaluable information throughout the project with regards what patients and their carers want from a melanoma support service. We were able to highlight areas which required change and expand on management approaches that were working well. From the focus group we met Ian Stone who became our patient representative and who has been an integral part of the project team. The outcomes from the patient focus group have been presented both Nationally and Internationally.

Each dermatology skin cancer link nurse has undertaken a comprehensive training programme which can now be used as a model for other nurses wishing to develop such an additional role. A dSCLN clinic runs weekly at each site (VHK, QMH) alongside the consultant tumour clinic. A melanoma patient will alternate their follow up between dermatology consultant and dSCLN. The dSCLN appointment is 30 minutes duration, allowing for a holistic needs assessment (HNA) to be performed. Patients now feel their wider needs are being identified and met. Evaluation has shown the optimum time to perform a HNA is at 7-10 days and at 9 months following diagnosis. A directory of services has been created as a signposting document for patients answering positively to the HNA. This directory of services has been shared with the Fife social care phase II TCAT project. It is envisaged that the future of this electronic directory of services will become a project in its own right. Local interest in the document has been shown by other cancer nurse specialists in Fife. It is a document that could be utilised within National information pathways. The role of dSCLN has been described as a ‘gold standard’ approach for a district general hospital. The Fife model has been mirrored in Dumfries and Galloway. Dermatology colleagues in the Borders also hope to set up a similar service.

Economic evaluation, comparing the pre TCAT follow-up model against the post TCAT follow-up model, shows a total cost saving of:
1 year follow up pathway - £3,840, £60 per patient, £2,760 per year*
5 year follow up pathway - £23,760, £360 per patient, £46,800 per year*
*calculated using 2015/2016 audit data, n=46 new 1 yr pathway patients/yr, n=26 new 5 yr pathway patients/yr, 130/year on 5 year follow up.

The introduction of a ‘personal plan’ has been welcomed by patients. The document provides a timeline of their forthcoming appointments. The personal plan includes a brief overview of the support, care and treatment to be expected. Following evaluation, all patients are now given a folder at the beginning of their melanoma management pathway. This acts as a ‘patient held record’, this is a record in which a patient can file their personal plan, patient information leaflets, self-monitoring photographs and copies of their clinic letters. Patients are encouraged to take this record with them to all appointments.

As part of the template of the dSCLN clinic a ‘rapid access slot’ was created. This is an urgent slot which can be filled by:
1) any melanoma patient under dermatology follow up who presents between appointments with a concerning lesion or potential metastases
2) any melanoma patient who has been discharged back to their GP who presents with a concerning lesion or potential metastases

A footnote is included in the ‘standard melanoma clinic letter’ which details to both patient and GP the alert symptoms requiring re-referral and how to refer. Evaluation of this process has been positive from
both patients and GPs. The process is clearly explained therefore it reduces patient anxiety on discharge and promotes self-management.

The development of an **electronic end of treatment summary** (EOTS) for all cancer patients is an aspiration for Macmillan and the Scottish government. A subgroup was formed as part of our project in the hope of creating a melanoma electronic end of treatment summary. Three available systems were considered in detail. A Forth Valley web based end of treatment summary system (TSUM) was thought to be the most appropriate for NHS Fife. Unfortunately, after a number of meetings and a visit from NHS Forth valley to load the TSUM system onto an NHS Fife computer, it was felt NHS Fife eHealth were not in a position to take this forward.

An important consideration when developing an EOTS is the need to communicate across regions. The majority of cancer patients in Fife are managed across Fife, SCAN and Tayside. Attempts were made by the SCAN TCAT lead to form a regional EOTS working party to take this forward at a regional level. Unfortunately, this was not possible.

In light of 1) the lack of development of an EOTS, 2) the requirement of a dictation guide for the dSCLN, and 3) the desire to copy patients into their clinic letters. A **standard melanoma clinic letter** was developed.

The **standard melanoma clinic letter** displays information in a structured way. Information which is useful to clinicians, patients and audit data collection staff is included. The letter includes a generic ‘footer’ which details information that is common to all melanoma patients and their GPs. The letter was constructed taking into account feedback from dermatology clinical colleagues and the SCAN primary care group. A ‘dictation prompt’ is visible in all dermatology clinic rooms to guide staff. All staff dictating melanoma letters follow this guide. All patients are offered the option of receiving a copy of their letter. Feedback has been positive from patients and their respective GPs, some minor suggestions for improvement have been made. The Fife **standard melanoma clinic letter** has been shared with other tumour groups across SCAN and dermatology colleagues nationally.

Taking into account feedback from the patient focus group a **melanoma workshop** programme was designed. The workshop promotes self-management and provides psychological support. The programme covers aspects which are common to all melanoma patients. The programme was designed such that if evaluation was positive it could be continued with no recurrent funding required. Delivery of the workshops demonstrates integration of staff across all areas: Maggie’s Fife, dermatology, plastic surgery, Fife Social Care, Fife Council and a patient representative. 5 workshops were delivered during the TCAT project. Evaluation has been positive, particularly with respect to **delivery from Maggie’s Fife**. Feedback suggest that the optimum time for a patient to attend a melanoma workshop is approximately 5 months after receiving their diagnosis. The long term aim is to have 3 workshops per year, attendance is to be regarded as a standard component of the melanoma patient pathway. Three workshops are planned for 2017.

**Melanoma workshop programme**

- Partnering your medical team – consultant dermatologist
- Emotional wellbeing – Maggie’s psychologist
- Advice about benefits – Maggie’s benefits advisor
- Community Connections – How Fife Council can support you
- Move more Fife – Fife Council
- Where now? – Head of Maggie’s centre
• Kitchen table informal discussion – tea and coffee

An unexpected outcome of the melanoma TCAT project has been the peer to peer review sessions between melanoma patients and our patient representative, Ian Stone, facilitated by Fife council local area co-ordinators (LAC). These sessions have provided valuable feedback with regards the melanoma patient pathway, melanoma TCAT phase I project, social care TCAT phase II project, and plastic surgery TCAT phase III project. The sessions have been so well received that Ian is continuing to offer these, facilitated by Fife council LAC.

A number of aspects of our project have demonstrated integrated working which has enhanced the experience for all the staff and patients involved in the journey. An electronic directory of services has been developed with Fife council local area co-ordinators. A joint presentation was given by the Fife TCAT dermatology, lung cancer and social care projects. All 3 projects contributed articles for the Fife TCAT newsletter. The melanoma workshop has brought together all providers. At present we are focussing on the Fife plastic surgery TCAT phase III project. We hope the success of our project will enable this integrated working to continue.

Scottish Government Cancer Strategy. Beating Cancer: Ambition and Action, March 2016. This document recognises that Scotland’s population is changing with a significant predicted increase in people aged ≥65 which will have an inevitable impact on the demand for health and social care, including cancer services. All aspects of the Fife melanoma TCAT project serve to equip staff and patients to deal with this increase in demand. The current integrated service provides us with a strong base from which we can make further improvements in the future.

A specific statement within the cancer strategy is ‘to help people make healthier choices to reduce their exposure to UV radiation’. Information given to melanoma patients along their pathway and in particular at the melanoma workshop, is specific to this aim. We hope to target the general population of Fife with a detect cancer early project in 2017.

In an attempt to ease the predicted future demand on cancer services, the cancer strategy aims ‘to ensure people are the lead partners in their care, able to make informed choices and know what is happening when and why.’ A number of aspects of this project have allowed us to enhance the ability of melanoma patients to be lead partners in their care:

- Personalised patient information and support including a personal plan and hand held patient record
- copy of standard melanoma clinic letter for patient
- melanoma workshop.

Cancer waiting time targets were first announced in Cancer in Scotland: Action for Change (2001). Better Cancer Care, An Action Plan (2008) reviewed and replaced these waiting times with two more challenging targets:

- a 31-day target from decision to treat until first treatment for all new cancer diagnoses (irrespective of the route of referral into the system); and
- a 62-day target from the date of urgent referral with suspicion of cancer to date of first treatment. This 62-day target includes referrals from national cancer screening programmes.

The integrated approach to working which has been central to the Fife TCAT melanoma project has enabled all teams involved to work together to ensure we continue to meet National cancer waiting time targets.
Through the auspices of the National Cancer Quality Steering Group (NCQSG), National Cancer Quality Performance Indicators (QPIs) were developed to drive continuous quality improvement in cancer care across NHSScotland. NHS Boards are required to collect data and analyse these on a yearly basis so that Regional Cancer Networks can then produce annual action plans to address any areas of variance or concern and report them via the relevant Regional Cancer Advisory Group. The Fife melanoma TCAT project has allowed the already close working relationship between dermatology and plastic surgery to develop further. This places the team in the best position to ensure we meet the melanoma QPI targets and work Nationally to improve the QPIs such that they provide a meaningful measure of quality.

Taken directly from the Scottish Government Cancer Strategy is a statement which we feel best describes the overall aim of the Fife melanoma TCAT project. To help people living with, and after, cancer treatment have access to information, advice and support tailored to their individual needs.

Future actions

We continue to disseminate the learned experiences of this project at a local, National and International level. Some aspects of this project are relevant to melanoma patients only, most are relevant to all types of cancer. Through the Scottish skin cancer group, Scottish dermatology society and the three National managed clinical networks we are working with colleagues across Scotland who are interested in adopting aspects of this project.

The future of the ‘directory of services’ remains undecided. This will be adopted as an individual piece of work. It is a document which is invaluable, it provides comprehensive local information with regards NHS, Fife council and 3rd sector services. Options are to maintain an up to date local document and/or share with National information portals such as NHS inform.

Following the success of the melanoma workshop it has been agreed, with the new head of Maggie’s Fife, that we will continue to provide 3 melanoma workshops per year based in Maggie’s Fife.

Development of the programme will be ongoing taking into account patient feedback.

Ian Stone is currently continuing to provide peer to peer patient review sessions, facilitated by Fife council local area co-ordinators. These provide a platform for patient support in addition to providing clinicians with constructive feedback. We have found patients are more at ease providing constructive feedback if no member of their clinical team is directly involved in the process.

Recurrent funding has been secured for the dermatology skin cancer link nurse role and clinics. Utilisation of this service is now embedded in the Fife melanoma patient pathway within dermatology. We will build on this to enhance awareness of this role across all specialities in primary and secondary care.

Patient feedback has highlighted that the decision of whether or not to have a sentinel lymph node biopsy is one that all patients find difficult. As part of the plastics phase III TCAT project we will develop information designed specifically to help patients with this decision.
Our most important focus for the future must lie with the earlier stages of the melanoma pathway. This includes patient presentation to their GP and appropriate referral by their GP to secondary care. 2015-2016 data shows that of those diagnosed with a melanoma in Fife 45% were referred ‘urgent suspicious of cancer’, the remaining 56% were referred by an alternative route. For a cancer that is visible on the skin by clinical examination the figure for referral ‘urgent suspicious of cancer’ is low. The ideal would be an increase in this percentage by approximately 30%. We have been awarded funding for 2 detect cancer early (DCE) projects which will allow us to focus on this important aspect of the patient pathway.

DCE 1 – GP lesion recognition and appropriate management
The aim of this project is that, ‘all patients should receive the right care, delivered in the right place, by the right person, the first time.’ We will develop the role of a ‘link dermatology GP/nurse practitioner’ in 7 pilot GP practices in Fife. If this is proven to be successful our aim would be to have a ‘link dermatology GP/nurse practitioner’ in each of the 60 GP practices in NHS Fife.

The link person will receive enhanced education focusing on:

1) recognition of benign and malignant skin lesions

2) appropriate referral of skin lesions,

3) appropriate management of skin lesions. We hope this will enable us to meet the aim documented above and thereby help manage the increase in incidence of skin cancer resulting from an ageing population and the current workforce issues in primary and secondary care.

DCE 2 – Public education on Fife beaches with regards sun protection and skin examination.
Funding has been awarded for this joint venture with Fife council. The aim of this project is to educate the general public with regards to sun protection and self-examination. Funding has been awarded for a number of permanent information plinths to be installed on the most popular Fife beaches. Life guards on Fife beaches will distribute information cards and free sunscreen over the summer months and similar information will be displayed in poster form on council notice boards.

Conclusion
The Fife melanoma TCAT projects phase I and III, in combination with the requirement to meet government waiting time targets and melanoma quality performance indicators, has resulted in the development of a melanoma pathway that provides quality clinical care which works synergistically with an enviable patient support service. We have a dedicated team, across a number of specialities, between whom there is great communication. This has enabled us to develop the Fife melanoma pathway and will allow us to build on these successes and meet future demands. We thank NHS Fife for recognising this by awarding the Skin cancer team with the ‘innovation award’ at the NHS Fife achievement awards 2017.

For additional information or to request a copy of the full report, please contact:
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The statistics in this report are the results of a self-evaluation carried out by local project staff with the 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.
What is TCAT

Transforming Care After Treatment programme is a £5 million five year programme funded by Macmillan Cancer Support Scotland.

**TCAT aims/objectives**

- To enable people affected by cancer to play a more active role in managing their own care.
- To provide services which are more tailored to the needs and preferences of people affected by cancer.
- To give people affected by cancer more support in dealing with the physical, emotional and financial consequences of cancer treatment.
- To improve integration between different service providers and provide more care locally.

**Phase 1 TCAT projects**
Background

Malignant melanoma of the skin is currently the 5th commonest cancer in Scotland. Melanoma has increased in incidence in Scotland over 50% in the last 10 years (ISD data). Approximately 60 melanomas are diagnosed in Fife each year. Scottish audit data from 2007 – 2011 shows a significantly higher proportion of thick melanomas (Breslow thickness > 4mm) in Fife than in other regions. The Breslow thickness of a melanoma is the most important prognostic indicator. Patients with a melanoma of Breslow thickness >4mm have a 10 year survival of 50%, compared with a 10 year survival of 92% in those with a melanoma of Breslow thickness ≤ 1mm. Referrals from primary care to dermatology continue to increase each year. Of the 8,000 referrals to the NHS Fife dermatology service each year 45% of them are skin lesions (33% benign, 12% skin cancer). The annual increase in dermatology referrals impacts on the capacity of the skin tumour clinic to meet the holistic needs of the melanoma skin cancer patient.

The South East Scotland Cancer Network (SCAN) has a regional skin cancer clinical nurse specialist based in NHS Lothian. In 2009 NHS Fife developed two ‘skin cancer link nurses’ (SCLN) at each of the two hospital sites, Victoria Hospital Kirkcaldy and Queen Margaret Hospital Dunfermline. The SCLN nurse role is as a dermatology nurse but with additional education and experiential learning in skin cancer. A SCLN nurse is always available at each hospital site (Monday- Friday 0800-1700hrs) An individual patient information pathway is completed for each patient. The role of the SCLN was to be present with the patient at the time the consultant informs them of their diagnosis. The SCLN nurse would arrange to meet with the patient and their family 7-10 days after a diagnosis. Contact details were exchanged and further meetings arranged as was required for the patient. The SCLN time was not timetabled, her role was unfunded and additional to other timetabled nursing care. Following active treatment, melanoma patients attend consultant led follow-up clinics in the department of dermatology. All consultant follow-up clinic appointments are of 10 minutes duration. The length of follow-up is determined by the Breslow thickness (prognostic indicator) of the melanoma. The follow-up documented below follows British Association of Dermatology Melanoma Guidelines.

- Breslow thickness ≤1 mm – follow up 3-4 monthly for 1 year.
- Breslow thickness >1 mm – follow up 3-4 monthly for 3 years, thereafter 6 monthly years 3-5.

Most patients have their primary melanoma lesion excised in the department of dermatology, this is classed as their treatment. Following this they will have a wide local excision (WLE) with a proportion also having a sentinel lymph node biopsy (SLNB). During the time period that the patient is getting their wide local excision +/- SLNB they are under the care of the plastic surgery team, this is normally a 5-month period. Thereafter melanoma patients are offered follow up in the dermatology department. Our pre TCAT model of conventional follow up clinics did not address a patients holistic and individual needs. A 10 minute consultant consultation did not tolerate for discussion about what matters to the patient and the support available. It did not allow for in depth discussion about the support available after treatment and how a patient would access this. Ideally by the time of discharge to primary care, all patients should be able to examine their own skin with confidence and be comfortable with appropriate measures of sun protection. The pre TCAT model did not allow rapid patient-led access back into secondary care once a patient had been discharged. We wished to build on the developments that had been made between 2009 -2013 and develop a new way of managing follow-up with a multi-partnership approach to maximize success.
Melanoma patient pathway Pre TCAT

- 10 minute dermatology consultant follow up appointments.
- Holistic needs not addressed unless patient volunteered an issue.
- SCLN time not timetabled.
- No pathway for referral back between follow up appointments or after discharge.
- Stage 2 of treatment with plastic surgery (5 months), no specific nursing support during this time.
Project Aims

The NHS Fife Melanoma project aims are to develop the melanoma patient pathway in line with the aims of the Macmillan transforming care after treatment programme. The specific aims of this project will be:

1) **To understand the experience of NHS Fife melanoma patients, improve the patient pathway and make changes to the service where appropriate** - this understanding will be gained by holding a patient focus group to discuss the existing service and aims of this project.

2) **Development of dermatology skin cancer link nurse clinic**
   - 2.1 - Development of SCLN clinic should make more efficient use of Consultant and nurse time.
   - 2.2 - Training undertaken to enable Skin Cancer Link Nurses (SCLN) to fulfill TCAT aims with regard to Holistic Needs Assessments (HNA) and SCLN clinics.
   - 2.3 - Holistic Needs Assessment (HNA):
     Introduce the use of HNA during the 30 minute appointment with SCLN.
   - 2.4 Personal plan:
     Introduce the Personal Plan for Melanoma Skin Cancer NHS Fife. The Personal Plan provides a brief overview of support, care & treatment.

3) **Introduction of an efficient system for rapid access back into secondary care.**

4) **End of Treatment Summary (EOT) to be created for all patients and:**
   - i) Sent to GP at the end of active treatment
   - ii) Sent to GP on discharge from dermatology follow up back to primary care.

5) **Patient “opt in” to copy of clinic letters**
   This allows for enhanced communication between patient and clinicians and will enable patient empowerment.

6) **Melanoma Workshop – patient self management**

7) **Development of plastic surgery skin cancer link nurse (PSSCLN)**
   This will follow the model of the dermatology SCLN. The role of a plastic surgery nurse will be developed to ensure a more detailed understanding of melanoma skin cancer. This will enable us to have a person who is a point of contact and support through the plastic surgery pathway. This role will be available to provide enhanced support to the more complex patients and to develop multi professional clinics and enhance support within the team. This development will allow enhanced communication between dermatology and plastic surgery.

   At the commencement of the TCAT project plastic surgery nursing staff did not have the capacity to develop this role.

   As of September 2016 the role of the plastic surgery skin cancer link nurse has been developed. **This aspect of our project will now be considered as a ‘stand alone’ phase 3 TCAT project.**
Diagram to illustrate the different aspects of the NHS Fife Dermatology TCAT project

- Plastic surgery SCLN
- Dermatology SCLN
- Rapid access back to secondary care
- Patient copy of clinic letters
- Electronic End of Treatment Summary
- Melanoma workshop
- Phase 3
Integration

Related Projects

Three other TCAT projects in Fife were also awarded funding.

1. Fife Council’s TCAT Phase 2 project, “Integrated Community Cancer Care” (ICCC) aiming to test the role of the Local Area Co-ordinator (LAC) within an integrated cancer pathway. The LACs help people affected by cancer deal with the physical, financial and emotional impact of a cancer diagnosis by supporting them to get the right information, access services and support in their local community (Appendix 1).

2. A model of best supportive care for patients with lung cancer, Phase 1 TCAT project. To develop and pilot a new model of care for patients with lung cancer who were for best supportive care.

3. Allied health professional (AHP) involvement is an important element of responsive, patient centred, holistic care. A successful bid for additional Scottish Government money secured £38,227 to implement an AHP project to run alongside and support the aims of the Fife TCAT lung cancer project. The aim of the AHP project was to ensure that all patients with lung cancer identified as requiring best supportive care had timely access to appropriate AHP interventions.

As the Fife TCAT projects became established it was recognised that there were significant benefits to be gained by amalgamating the steering groups of the TCAT lung cancer project, TCAT melanoma project and Fife Council’s Phase 2 project in order to facilitate integrated strategic planning and avoid duplication of effort.

Integration of the Fife TCAT projects

- Formation of a joint steering group – Fife strategic TCAT steering group.
- Production of a joint newsletter (Appendix 2).
- Joint presentation by all 3 Fife TCAT projects at SCAN TCAT Learn and share event – ‘Integration and co-ordination, a patient centred approach in Fife.’
- Direct referral to Phase 2 project, “Integrated Community Cancer Care” (ICCC) test the Local Area Co-ordinator (LAC).
- Peer to peer sessions, led by “Integrated Community Cancer Care” (ICCC) and the LAC and Ian Stone (Fife melanoma project patient rep).
- Directory of services – written by Elaine Hancock (dSCLN), shared and added to by Fife council Integrated Community Cancer Care” (ICCC).
- Melanoma workshop – held in Maggie’s Fife. Presentations by Maggie’s staff, dermatology, plastic surgery, LAC and patient representative.
Core Data Process

All Macmillan funded TCAT projects required NHS Boards and Local Authorities to collect a minimum core dataset. This local data will be used within national evaluation to gather data across Scotland and focus upon similarities and differences in processes and resulting actions.

For the NHS Fife Melanoma TCAT project, core data was collected on all patients who were seen at the Skin Cancer Link Nurse clinic. Each patient had a Holistic Needs Assessment (HNA) performed. A pro forma was developed and completed by the Skin Cancer Link Nurse for every patient who had a HNA. The pro forma can be found in the appendices section at the end of the report (Appendix 3). The data collection period was from 18/05/2015 – 31/07/2016 and produced 147 records (13 patients had a second HNA). The following core data results are based on 134 patients who had a diagnosis of melanoma and were seen by a skin cancer link nurse SCLN at a hospital outpatient appointment. In some instances data was not recorded or not known and this is reflected in the total number of patients where applicable.

Figure 1: Gender

Figure 2: Scottish Index of Multiple Deprivation (SIMD)

Figure 3: Age range

Figure 4: Economic activity
**Figure 5: Performance Status (ECOG)**

![Performance Status (ECOG) chart](chart)

**Figure 6: Current living situation**

![Current living situation chart](chart)

**Figure 7: Melanoma primary / recurrence**

![Melanoma primary / recurrence chart](chart)

**Figure 8: Seen by SCLN**

![Seen by SCLN chart](chart)
Comment regarding Core data

In this project:

- The patient group included was composed of 50% male and 50% female.
- Of these the majority were over 50 years old. Approximately 15% were aged between 30-49 years old, less than 5% were under 30 years old.
- There was an equal split between the number that were retired compared with those that were employed. Less than 5% were unemployed or looking after the home.
- This is reflected in an approximately equal split across the indices of deprivation (SIMD) from 2-5 (5 = least deprived), a lower number were in SIMD 1 = most deprived.
- The majority were healthy with a performance status (ECOG) of 0.
- Eighty percent lived with a spouse or children/relatives.
- Less than 20% lived alone.
- The majority (96%) presented with a primary melanoma, the remainder presenting with a recurrence.
- There was an approximately equal split between patients seen by the VHK SCLN, (Elaine Hancock) and the QMH SCLN, (Carol Scorgie).
Aim 1 - To understand the experience of NHS Fife melanoma patients

To understand the needs of NHS Fife melanoma patients.
To make the patient pathway.
To make it more patient centred and make changes to the service where appropriate.

A Patient Focus Group Meeting was arranged to achieve the following:

- Share initial ideas for our project with patients and gain feedback.
- Identify areas suitable for inclusion in the melanoma workshop programme (Health and wellbeing workshops).
- Identify patients who wished to be actively involved – recruit a patient representative.

The Patient Focus Group meeting was held on 6th November 2014. Invitees were patients who had received a diagnosis of melanoma, their spouses/partners, family member or carers. Members of staff in attendance included: Fife Dermatology Consultant and project lead, Skin Cancer Link Nurses, NHS Fife Lead Cancer Nurse, Cancer Audit Facilitator/TCAT local evaluation lead and SCAN Patient Involvement Manager/Macmillan Project Manager.

Twenty people attended the focus group and were split into 3 smaller groups for informal discussion. Different areas were identified for discussion and information gathering to better understand:

1. What happens when a patient receives a diagnosis
2. The level of support required by patients
3. How patients and carers perceive NHS Fife’s effectiveness in meeting their needs
4. What impact responsibilities outside of health have on a patient and their family when living with cancer
5. The importance of psychological and social support in helping patients and their families cope with living with cancer.

Outcomes and actions from information gathered at patient focus group:

1. Consider how best to deliver a melanoma diagnosis – face to face, suggest the patient brings a relative/carer with them. Clinicians to consider asking patient preference between phone call/face to face at the initial clinic visit. This can only be done for those in whom there is a strong suspicion of melanoma.
2. Biopsy results confirming a diagnosis to be delivered within 4 weeks.
3. Sentinel lymph node biopsy results from Tayside to be delivered more quickly. Plastic surgery skin cancer link nurse to phone patients with a negative result.
4. Continue to offer the 7-10 days appointment with the Skin Cancer Link Nurse following diagnosis.
5. Feedback is that the SCLN are invaluable to the patients.
6. Provide information on how to access the service between appointments or after discharge. This is now documented within the ‘footer’ of all standard melanoma clinic letters sent to patients and their GP.
7. Remind GPs how to access the service between appointments or after discharge. This is now documented within the ‘footer’ of all standard melanoma clinic letters sent to patients and their GP.
8. Patients are to be offered the option to opt in/out of receiving a copy of their clinic letters. There was a 50/50 split between those wanting a copy and those not wanting one, therefore staff cannot assume that a patient will want a copy of their clinic letter. The Dr/SCLN must ask the patient their preference and document this within the standard melanoma clinic letter.
9. Alternating clinic visits between Consultant and SCLN was well received. This is the one aspect of the project where recurrent funding is required (2 nurse band 5 sessions per week). The aim is to ensure this service continues after the TCAT project ends.

10. A Holistic Needs Assessment will be performed. This is now current practice – see results reported under aim 2.2.

11. The opportunity to attend a Melanoma Self Management Workshop was well received. This is now current practice – see results reported under aim 6.

12. The value of psychosocial support from meeting fellow patients was recognized. It is hoped that similar support can be offered at the melanoma workshop.

13. From the patient focus group we have been able to identify a patient representative (Mr Ian Stone) who has become a very active member of the dermatology phase 1 and social care phase 2 project teams.

A poster detailing the results from the ‘patient focus group’ has been presented at the Scottish dermatology society meeting in February 2016 and the world congress of skin cancer in Vienna in September 2016.

The full report and poster can be found at the end of this report. (Appendices 4 & 5)
Aim 2.1 – Development of a dermatology Skin Cancer Link Nurse (SCLN) clinic

Patient - development of the SCLN clinic should allow more time so as a patients unmet holistic needs can be determined and addressed. Service - development of SCLN clinic should make more efficient use of Consultants time. Service – development of SCLN clinic should be cost effective.

Prior to the introduction of the TCAT dermatology project, all patients would receive a 10 minute dermatology consultant review appointment.

The TCAT project did not attempt to change the number of hospital follow-up appointments required by each patient. The TCAT project has enabled follow-up appointments to alternate between dermatology consultant and dermatology SCLN. For the duration of the TCAT project the SCLN appointment was 30 minutes allowing for a holistic needs assessment (HNA) and evaluation to be performed.

This aim of this change was to:

- Allow more time during the SCLN review appointment to determine whether patients have unmet holistic needs. This should enable people with cancer and their families to feel their wider needs are being identified and met.

- Free up consultant appointment slots which could then be used to see more ‘new urgent’ cancer referrals or patients with ‘complex needs’.

- This should enable clinicians to maintain high quality care with the increasing incidence in skin cancers.

Table 1: Breakdown of SCLN appointments (18/05/2015 – 31/07/2016)

<table>
<thead>
<tr>
<th>SCLN</th>
<th>Grand total of clinic appts</th>
<th>Review appts</th>
<th>7 – 10 days appts</th>
<th>Emergency appts</th>
<th>Seen outwith clinic as 7-10 day</th>
<th>Seen outwith clinic as emergency</th>
</tr>
</thead>
<tbody>
<tr>
<td>EH</td>
<td>147</td>
<td>101</td>
<td>24</td>
<td>22</td>
<td>12</td>
<td>8</td>
</tr>
<tr>
<td>CS</td>
<td>89</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NK</td>
<td>NK</td>
</tr>
<tr>
<td>Total</td>
<td>236</td>
<td>101</td>
<td>24</td>
<td>22</td>
<td>12</td>
<td>8</td>
</tr>
</tbody>
</table>

Section 2.3 Holistic Needs Assessment details the utilisation of the HNA, patient signposting and patient evaluation of this development.
SCLN patient contact outwith scheduled appointments

Pre and post TCAT SCLN contact outwith scheduled appointments was audited and provided the following conclusions:

- The nature of the calls has changed post TCAT.
- The introduction of the personal plan may have prevented outpatient issues.
- Having had the opportunity to discuss concerns by use of the HNA may have resulted in reduced calls regarding worry, insurance, post operative issues etc.
- Post TCAT the main reason for SCLN contact was new lesions - reference to TCAT Aim 3 - Rapid access system back to secondary care.
- Although the SCLN contact has not reduced post TCAT, the nature of the calls appear less varied and more centred on seeking advice on new lesions – patients are choosing to contact SCLN rather than attend their GP.
- There is a robust pathway for contacting SCLN, this has been highly promoted within Primary Care.
- Patients are self managing and identifying new lesions.
- The above findings confirm that the continuation of the newly developed role of the SCLN is essential in both ensuring our patients are empowered and to contribute to a highly effective and efficient service.
The following pages details a health economic evaluation of the SCLN clinic within the dermatology TCAT project, this evaluation was kindly performed by Edinburgh Napier University as part of the national evaluation of the TCAT programme.

NHS FIFE MELANOMA TCAT HEALTH ECONOMIC EVALUATION

The aim of the health economic evaluation for this project was to:

- Compare the cost of the new TCAT pathway with the previous pathway.
- Set out visually the 2 pathways and identify service use.

Summary

In terms of cost minimisation (i.e. where cost is the only outcome measure) (McFarland 2014), the TCAT service dominates. For the 130 TCAT patients the new pathway “costs” £27,600 less than the one it replaced.

For patients on the <1mm 12 month pathway there is a cost saving of £60 per patient.

For patients on the >1mm 5 year pathway there is a cost saving of £360 per patient.

The TCAT service has increased provision of rapid access back to secondary care during follow up and probable reduction in waiting times. Importantly, the service has also increased the efficiency of the melanoma clinics overall. The introduction of the holistic needs assessment, which promotes patient self-management, could also contribute to the efficiency of clinics by reducing medically unnecessary ‘additional’ appointments as patients are supported better to self-manage.

Comparing the pathways

The follow up pathway for patients diagnosed with a melanoma is determined by the Breslow Depth: <1mm is 12 months follow up, over >1mm is 5 years follow up. Prior to TCAT all follow up patient appointments were undertaken by a consultant. The TCAT project introduced a change in the workforce resource used to staff the pathways. The new pathway provided for 50% of review appointments being seen by a consultant and 50% by a Skin Cancer Link Nurse (SCLN).

Data used in evaluation

Since the start of the TCAT project the diagnosis of patients based on Breslow Depth is shown in the Table below.

<table>
<thead>
<tr>
<th>Breslow</th>
<th>Number of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1mm</td>
<td>64</td>
</tr>
<tr>
<td>&gt;1mm</td>
<td>66</td>
</tr>
<tr>
<td>Not assessable</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>134</td>
</tr>
</tbody>
</table>
We have based the findings on the pathways experienced by 130 people who were assessable and also data provided for the workload of one SCLN for the duration. Illustrating whether clinic appointments were follow up, post-diagnosis or 'rapid access'.

Costs were obtained from the ISD Costs book for Outpatient costs (ISD 2016). Consultant costs were for Consultant Outpatient Appointment Oncology cost per attendance for NHS Fife. Costs for the SCLN were for Outpatient Nurse Led Clinics Oncology. No NHS Fife specific costs were available therefore national averages were used.

<table>
<thead>
<tr>
<th>Cost per attendance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultant appointment</td>
</tr>
<tr>
<td>SCLN appointment</td>
</tr>
</tbody>
</table>

### <1mm Breslow Depth

#### Pre- TCAT Pathway

<table>
<thead>
<tr>
<th>Appointment type</th>
<th>Number of follow up appointments</th>
<th>Cost per patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultant</td>
<td>3</td>
<td>£582</td>
</tr>
<tr>
<td>SCLN</td>
<td>0</td>
<td>£0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>3</td>
<td><strong>£582</strong></td>
</tr>
</tbody>
</table>

Total number of patients x cost per patients = 64 x 582= £37,248

#### TCAT Pathway

<table>
<thead>
<tr>
<th>Appointment type</th>
<th>Number of follow up appointments</th>
<th>Cost per patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultant</td>
<td>2</td>
<td>£388</td>
</tr>
<tr>
<td>SCLN</td>
<td>1</td>
<td>£134</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>3</td>
<td><strong>£522</strong></td>
</tr>
</tbody>
</table>

Total number of patients x cost per patients = 64 x 522= £33,408

Cost savings by implementing TCAT pathway in this patient group= 37248-33408= £3,840
For patients on the <1mm 12 month pathway there is a cost saving of £60 per patient or £2,760 per year* (*calculated using 2015/2016 audit data, n=46 new patients per year).

For patients on the >1mm 5 year pathway there is a cost saving of £360 per patient, or £46,800 per year* (*calculated using 2015/2016 audit data, n=26 new patients per year, 130 on 5 year follow up at any one time).

This amounts to approximately 1wte band 5 mid point – i
**Introduction of a rapid access/ urgent (follow up or return) appointment slots**

The introduction of the TCAT Pathway introduced capacity for the development of a ‘rapid access/ urgent (follow up or return) appointment slot. Within the SCLN clinic template there now are 5 standard review slots and 1 urgent slot each of which are of 30mins duration.

Pre-TCAT patients requiring to be seen urgently between review appointments or after discharge would be added to an already fully booked consultant clinic list, or given a ‘new urgent tumour slot’. This did not allow time to fully explore a patients needs and reduced the number of slots available for new ‘urgent suspicious of cancer’ referrals.

Clinic appointment allocation data from one SCLN during the TCAT project illustrates that 15% of all clinic appointments were ‘rapid access’. This allows a patient who develops a problem between follow up appointments to phone and be given a slot without having to see their GP or wait for the relevant dermatology consultant to be contacted. Moreover if a melanoma patient develops a concern after discharge from the follow up pathway they are advised to see their GP who will refer urgently. At the point of triage this patient can be given a SCLN urgent clinic slot.

At discharge the patient knows how to access the department again if required. This is detailed within the footer of the ‘standard melanoma clinic letter‘ that the patient is copied into. Qualitative feedback from patients has told us that the provision of rapid access back to secondary care has:

- alleviated patient anxiety
- reduced waiting times
- enabled consultant clinic to run to time, SCLN 30minute time slot and use of the HNA has allowed us to address psychological distress in a managed way.
- freed up new patient ‘tumour assessment clinic’ slots when compared with old pathway

**Improved Efficiency of Clinic, that supports patient self-management**

Improvements which cannot be captured by economic analysis but have occurred as a result of the new pathway include better and more efficient running of the clinic.

Previously patients were seen in an adhoc reactive manner, now a set SCLN clinic with dedicated appointments has been set up. This has resulted in the charge nurse being able to allocate staff appropriately and ensure the department is run as efficiently as possible.

In addition, Consultant staff within the department also know the day and time on which the SCLN clinic takes place. The clinic template, into which patients can be booked, enables all dermatology consultants to utilise this clinic from whichever site they are working without the need to locate and communicate with the SCLN as to when there maybe an appropriate time for her a patient. This is invaluable to the efficiency of the running of the service and the utilisation of the SCLN clinic, in particular because all consultant dermatologists work on split sites and the majority work part time compared to the SCLNs who work on one site and are full time.

At each SCLN appointment patients have the opportunity to participate in an holistic needs assessment. This assessment is carried out by the SCLN and allows for patient’s concerns to be discussed. Referrals and signposting can then occur to the most appropriate place. This is seen to provide supported patient self-management during and after follow up.
Limitations to the health economic evaluation

The economic analyses presented in this report display a number of limitations, namely:

- Patient outcome of alternating appointments not available, therefore it is assumed that the outcome of the old and new pathways are the same
- Data only available for one SCLN’s appointments
- No further information beyond number of appointments available

To enable further economic focused analysis, the collection of patient outcome data and data on the services/support that patients used post HNA should be collected. Collection of quality of life data could enable a cost effectiveness analysis in terms of the cost of delivering changes to quality of life using different patient pathways (i.e. TCAT and non TCAT). This information should be available on an individual patient level and on at least two time points. Collection of quality of life data prior to the patient engaging with any melanoma service and after would enable a calculation of any improvements in quality of life potentially delivered by the service under evaluation. Collection of quality of life data at the same time points across different follow up pathways (i.e. TCAT and non TCAT) would enable these changes in quality of life to be calculated for different models of follow up. Combining this data with resource use data would enable the calculation of the cost effectiveness of each model under comparison. Collecting quality of life data using an instrument such as EQ5D (The EuroQol Group 1990) would allow the calculation of QALYs gained by each model, allowing for the calculation of cost utility in terms of cost per QALY gained.

References
Experiential learning and Education undertaken to enable Skin Cancer Link Nurses (SCLN) to fulfill TCAT aims with regard to Holistic Needs Assessments (HNA) and SCLN clinics.

Below are details of all Experiential learning and Education undertaken by SCLNs:

<table>
<thead>
<tr>
<th>Date</th>
<th>Skin Cancer Link Nurse</th>
<th>Training</th>
<th>Provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>24/04/2015</td>
<td>Elaine Hancock &amp; Carol Scorgie</td>
<td>Dermoscopy</td>
<td>NHS Tayside</td>
</tr>
<tr>
<td>2015</td>
<td>Elaine Hancock &amp; Carol Scorgie</td>
<td>Holistic Needs Assessment Training</td>
<td>In House</td>
</tr>
<tr>
<td>May 2015</td>
<td>Elaine Hancock &amp; Carol Scorgie</td>
<td>Hands on organomegaly &amp; lymph node examination</td>
<td>In house - Haematology Consultant clinic and within Dermatology clinic</td>
</tr>
<tr>
<td>23/06/2015</td>
<td>Elaine Hancock &amp; Carol Scorgie</td>
<td>Implementing the recovery package Survivorship &amp; supported self care 1 day interactive workshop</td>
<td>Macmillan Cancer Services</td>
</tr>
<tr>
<td>20/09/2016</td>
<td>Elaine Hancock</td>
<td>MsC Nursing / health studies (clinical practice). 9 month course.</td>
<td>Dundee University School of nursing</td>
</tr>
<tr>
<td>Jan 2017</td>
<td>Elaine Hancock</td>
<td>Prescribers course</td>
<td>Dundee University School of nursing</td>
</tr>
</tbody>
</table>

Both were already highly skilled dermatology nurses, however over a 1-year period a significant amount of time was invested by both SCLNs in Experiential learning and Education. This has enabled them to manage all aspects of the SCLN nurse-led clinic. For a 6 month period additional consultant observation and instruction was offered with every patient that each SCLN examined in clinic. Both nurses attended a dermoscopy course and the use of the dermatoscope was introduced when examining every clinic patient. A significant amount of time was spent determining the best method of introducing the holistic needs assessment and thereafter evaluating the use of this. Macmillan cancer services offered useful guidance with this aspect of the project.

Both nurses invested a great deal of time in attending the Dundee School of Nursing clinical practice course. This course required dedication in view of the amount of coursework required over a 9 month period. This coursework was supervised by Dr Mowbray (VHK) and Dr Fraser (QMH). Elaine Hancock (VHK) is to be congratulated for completing the clinical practice course. This has given her a good basis for running her own nurse-led clinic. Unfortunately due to illness, Carol Scorgie was unable to complete the course. Despite this she attended the majority of the study days and has gained useful experience from this which she has been able to put into clinical practice. In order to further her training and development, Elaine Hancock will complete a non medical prescriber’s course in 2017.

The success of the nurse-led SCLN clinics is due to the dedication and enthusiasm shown by both SCLN. This is demonstrated by the observation that both nurses are now sufficiently skilled such that each of the SCLN clinics can run on a weekly basis with or without consultant presence.
2.3 Holistic Needs Assessments (HNA)

Introduce the use of the HNA during the 30 minute appointment with the SCLN.

The majority of melanoma patients are ECOG Performance Status 1 (fully active, able to carry on all pre-disease performance without restriction). The purpose of the Holistic needs assessment (HNA) is to determine if NHS Fife melanoma patients have any unmet holistic needs. (Appendix 6)

The TCAT project has allowed us to introduce the HNA during a 30 minute appointment with the SCLN. All patients, whatever time point they were in their melanoma pathway, were asked to complete a HNA. The results have enabled us to determine the most useful time point within the patient pathway to introduce the HNA.

<table>
<thead>
<tr>
<th>HNA Split by SCLN</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCLN - EH</td>
<td>76</td>
<td>57</td>
</tr>
<tr>
<td>SCLN - CS</td>
<td>58</td>
<td>43</td>
</tr>
<tr>
<td>Total</td>
<td>134</td>
<td>100</td>
</tr>
</tbody>
</table>

**Figure 9: Length of consultation**

- There is a weak correlation between the number of concerns and the length of appointment.

**Figure 10: Time from diagnosis to TCAT Skin Cancer Link Nurse appointment**

- Patients usually have their first SCLN appointment 7-10 days after they find out their diagnosis. This data uses the diagnosis date as the histological date. A number of patients were included in the TCAT project who had been under follow up for years, as demonstrated by the number at 2+ and 3+ years.
• Figure 10 demonstrates that the HNA was performed at a varied number of time points in the patient pathway.

**Figure 11: Treatment status – still receiving treatment?**

![Pie chart showing treatment status](image)

- The majority had completed ‘active treatment’ at the point of completing their HNA. Of the 31% receiving active treatment, the majority completed their HNA within 7-10 days of receiving their melanoma diagnosis.
Number of concerns by time

**Figure 12: Number of concerns by time**

3 Year + - HNAs were not available to these patients at the time of their diagnosis

- Complete data to carry out this analysis was available for 112 patients, and shows that as the time between diagnosis and appointment increases, the percentage of patients reporting concerns decreases.

- SCLN clinic slots will remain at 30 minutes whether a HNA is to be performed or not. This is to allow flexibility as from clinical experience there are always patients attending the parallel consultant clinic who will require introduction to/input from the SCLN.

Number of concerns by treatment status

**Table 4: Number of concerns by active treatment or no active treatment**

<table>
<thead>
<tr>
<th></th>
<th>Still receiving active treatment</th>
<th>Not still receiving active treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>No concerns</td>
<td>59.5% (25)</td>
<td>80.4% (74)</td>
</tr>
<tr>
<td>1 or more concerns</td>
<td>40.5% (17)</td>
<td>19.6% (18)</td>
</tr>
</tbody>
</table>

**Figure 13: Number of concerns by treatment status**

- Table 4 and figure 13 show that a greater percentage of patients who are still on active treatment report 1 or more concerns (40.5%) compared to the cohort of patients no longer on active treatment (19.6%).

HNA to be performed at:
- 7-10 days
- 9 months
Holistic Needs Assessment Concerns

- The majority of patients had no concerns (74%).
- Of the patients who had one or more concern, 69% had 3 or under concerns.

**Table 5: HNA Concerns**

<table>
<thead>
<tr>
<th>Specific concerns</th>
<th>Concern</th>
<th>% of total specific concern</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>sleep problems/nightmares (7),</td>
<td>46.2</td>
</tr>
<tr>
<td></td>
<td>tired /exhausted and fatigue (7)</td>
<td></td>
</tr>
<tr>
<td>Practical</td>
<td>insurance/travel (3)</td>
<td>23.1</td>
</tr>
<tr>
<td>Family/ relationship</td>
<td>Children (3)</td>
<td>42.9</td>
</tr>
<tr>
<td>Emotional</td>
<td>worry, fear or anxiety (8)</td>
<td>29.6</td>
</tr>
<tr>
<td>Spiritual or religious</td>
<td>loss of meaning or purpose of life (2)</td>
<td>50</td>
</tr>
<tr>
<td></td>
<td>Not being at peace with or feeling regret about the past (2)</td>
<td></td>
</tr>
<tr>
<td>Lifestyle</td>
<td>Exercise or activity (7)</td>
<td>33.3</td>
</tr>
</tbody>
</table>

**Overall top 5 concerns**

1. Worry, fear or anxiety (8)
2. Sleep problems/ nightmares (7)
3. Tired/exhausted or fatigue (7)
4. Exercise or activity (7)
5. Sun protection (6)

- Table 5 demonstrates that despite the fact that the majority of melanoma patients are healthy, having a good performance status (ECOG 0 or 1), one quarter of melanoma patients do have concerns. The majority of these concerns are unlikely to have been learned without the introduction of a HNA. We conclude that enhanced input at an early stage with an HNA assessment and targeting of any issues highlighted would hopefully have a general economic advantage for this relatively healthy group of working patients.
Referrals

**Figure 14: Were any formal referrals made?**

- Yes: 7%
- No: 93%

**Figure 15: Was the patient signposted to other sources of advice?**

- Yes: 5%
- No: 95%

Of the 9 formal referrals patients were referred to:
- Cancer specific third sector organisation/charity (7, 78%)
- To their own GP (1, 11%)
- To NHS general (non cancer service (1, 11%)

Of the 7 patients signposted:
- Cancer specific third sector organisation/charities (3, 43%)
- Other (missing, patient transport) (2, 29%)
- Your local TCAT project (1, 14%)
- Their own GP (14%)

**Formal referral to Local Authority for social care assessment**

1 patient (0.7%) was formally referred to the Local Authority for social care assessment
Patient questionnaire - question 6- Did you find the holistic needs assessment worthwhile and helpful?

Data was missing for 20 questionnaires, for the remaining 94, the results are shown below

- 60/94 (63.8%) of patients found the HNA worthwhile and helpful by scoring 10
- 34/94 (36.1%) scored this as less than 10
- 14/94 (14.8%) scored this as 5 or less

<table>
<thead>
<tr>
<th>Score</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>3</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>7</td>
<td>5</td>
<td>2</td>
<td>5</td>
<td>8</td>
<td>60</td>
</tr>
<tr>
<td>Percentage</td>
<td>3.2</td>
<td>0</td>
<td>2.1</td>
<td>2.1</td>
<td>7.4</td>
<td>5.3</td>
<td>2.1</td>
<td>5.3</td>
<td>8.5</td>
<td>63.8</td>
</tr>
</tbody>
</table>

Unfortunately the patients who scored below 10 did not provide further information on the questionnaire as to why they did not find the HNA worthwhile and helpful.

Patients were asked to rate the ‘helpfulness of the HNA’. Of the 34 patients who score the HNA less than 10, only 4 patients had concerns 2 of which did not relate to their melanoma. The remaining 2 patients had their concerns addressed and they scored the HNA as 9. This concludes that the majority of patients who did not find the HNA helpful had no concerns.
Directory of services

As part of the process of setting up the HNA assessment it was recognized a ‘directory of services’ was required. This has been created. This is a comprehensive document initially created by Elaine Hancock (SCLN, VHK). This document serves as a directory with information about local, regional and National services available should a patient answer the HNA positively.

The directory of services has been shared with the Social care Fife phase 2 TCAT project, who have added to the document. It has been agreed that until the close of the phase 2 project, Alison Watt (phase II project lead) will oversee a 6 monthly update of the directory of services.

A number of other NHS Fife cancer nurse specialists have expressed an interest in getting involved in the use of and updating of this directory of services.

The directory of services could also be used at a National level by NHS inform.

‘The future of the directory of services’ is an item which will be addressed following the completion of this phase 1 TCAT project.

A sample page of the Directory can be found in appendix 7.
Introduction of the Personal Plan for Melanoma Skin Cancer patients in NHS Fife. The personal plan provides a brief overview of the support, care & treatment to be expected, including a Personal Plan.

**Patient information sheet**

**Melanoma skin cancer patients, NHS Fife**

We hope this information sheet will give you an overview of what to expect with regards to the support, care and treatment you will receive following the diagnosis of a melanoma skin cancer.

**Dermatology follow up appointments**

Your appointments will alternate 4 monthly between your dermatology consultant and your dermatology skin cancer link nurse. At both clinics we will check your melanoma site, perform a whole body skin check and check for enlarged nodes. Extra time will be allowed at your dermatology skin cancer link nurse appointment, this will allow you to discuss any other issues you may have. A dermatology consultant will always be available when you attend the skin cancer link nurse clinic.

**Skin self examination**

By the time you are discharged from dermatology follow up you will be confident in examining your skin for suspicious lesions.

- We will help you learn how to do this be performing a whole body skin check at your review appointments and encouraging you to become familiar with your skin.
- ‘Skin self examination' will be included as a topic in the programme for the 'melanoma skin cancer patient self management group', all melanoma skin cancer patients will be invited to attend this group meeting.

**Photographs of your skin/moles**

When you attend your melanoma review clinic in the dermatology department we will assess your skin and determine whether 'whole body photographs' would be useful to aid self examination. If we think these would be useful, a copy will be given to you to keep at home.

**What to do if you find a lesion/lump that you are concerned about**

If you find a concerning lesion/lump **while you are under follow up in the dermatology department**. You should telephone your skin cancer link nurse, she will organise an urgent appointment.

If you find a concerning lesion/lump **after you have been discharged back to your GP**. You should make an appointment with your general practitioner. Your GP will refer you urgently to dermatology.
Referral by GP, seen in clinic, diagnosis of melanoma made by taking a skin biopsy

Seen by Consultant and diagnosis of melanoma given. Time with skin cancer link nurse (SCLN) to discuss diagnosis

Return to see skin cancer link nurse – discuss treatment plan, answer any concerns or queries

Wide local excision (removal of skin around the melanoma site) +/- sentinel lymph node biopsy (operation to remove the draining lymph node which is sent for analysis) (plastic surgery or dermatology)

Review dermatology consultant
Check melanoma site, whole body skin check, check for enlarged nodes, consider whole body photographs

Review skin cancer link nurse
30 minute appointment
‘Holistic Needs Assessment’ (time to talk about what is important to you and what support might help
Check melanoma site, whole body skin check, check for enlarged nodes

Follow up, how often you are seen depends on the thickness of your original melanoma:
Melanoma Breslow less than 1mm – seen 4 monthly for 1 year approximately
Melanoma Breslow greater than 1mm or mitotic rate greater than 1 – seen 4 monthly for 3 years, then 6 monthly up to 5 years

### Personal plan

<table>
<thead>
<tr>
<th>Appointment</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dermatology consultant clinic (diagnosis discussion)</td>
<td></td>
</tr>
<tr>
<td>Dermatology Skin Cancer Link Nurse Review</td>
<td></td>
</tr>
<tr>
<td>Plastic surgery consultant (clinic)</td>
<td></td>
</tr>
<tr>
<td>Wide Local Excision +/- sentinel lymph node biopsy operation</td>
<td></td>
</tr>
<tr>
<td>Plastic surgery post op review</td>
<td></td>
</tr>
<tr>
<td>Dermatology consultant review (clinic)</td>
<td></td>
</tr>
<tr>
<td>Dermatology skin cancer link nurse review</td>
<td></td>
</tr>
</tbody>
</table>
To establish the effectiveness of the Personal Plan every patient was asked for feedback in the form of a questionnaire. This questionnaire was offered to the patients at each SCLN clinic appointment and was completed in clinic. Patients were at different stages of the melanoma pathway when completing the questionnaire therefore some questions were not applicable.

135 questionnaires were completed between 18/05/2015 and 03/08/2016. 10 questionnaires were removed as these patients had completed 2, the second questionnaire was removed in these instances. 11 questionnaires were removed because they were blank. There were 114 questionnaires so the response rate of the questionnaire was 84.4%.

**Question 4 – Did you find your personal plan useful, i.e. information and a good visual aid?**

Data was missing for 33 questionnaires, for the remaining 81 the results are shown below

- Over 75% found the personal plan useful. 25% found it less useful. We wonder whether this is in part because at discussion of their diagnosis and management each patient is given a lot of different information leaflets including the personal plan. For some it is likely the personal plan is lost in amongst this paperwork. We will introduce the use of a patient held record for each patient. The record will be used to file all paperwork given to the patient regarding their melanoma. Clinic letter copies and photographs can also be stored in this record. The personal plan will be filed at the front of this record. The patient will be asked to take the record with them to all appointments – dermatology, plastics, oncology.
Aim 2 - Patient questionnaire, additional results

- The majority of patients felt they received adequate information from their dermatology consultant and dSCLN following their initial diagnosis.
- The majority of patients felt they received adequate information from the plastic surgery service about the treatment they were to have.
- The majority found support from the dSCLN helpful.
- The majority found the length of the appointment time with the SCLN to be adequate.
- The majority of patients were happy with their follow up arrangements after completion of their active treatment.
- 50% felt confident that they could carry out a self examination, recognize a worrying lesion and use sun protection adequately. It should be remembered that this question was asked of patients at all time points in their pathway. We would hope that at the point of discharge this question would be answered more positively. Of note, after attendance at the melanoma workshop 75% felt very/more confident in managing their condition, 25% felt the same as before with no one answering that they did not feel confident. The melanoma workshop programme will continue to include a section on ‘skin examination’ and ‘sun protection’. The standard melanoma letter (see Aim 4, page 37 includes a ‘footer’ that details ‘Alert symptoms requiring re-referral – change in skin at site of melanoma. Change in colour, shape or size of an existing mole. New growing nodule with or without pigment. Lymphadenopathy or organomegaly.’ This will continue to be included in the standard melanoma letter.
- The majority rated their overall experience to be high.
- Occasionally a patient had concerns regarding their pathway from GP diagnosis and referral to first hospital appointment. This part of the pathway is out with the realms of this project. It is hoped that the introduction of the standard melanoma clinic letter will highlight the importance to GPs of the melanoma patient pathway, highlight important prognostic and management factors, detail support services available and generally increase awareness of appropriate management. Dr Mowbray has secured funding for a ‘detect cancer early’ project which will focus on the recognition of benign and malignant skin lesions by GPs and appropriate management/referral of these lesions.
Introduction of an efficient system for rapid access back into secondary care.

One of the 6 slots in the dermatology SCLN clinic will be an ‘urgent’ slot. This slot will be reserved for patients who require rapid access back into the system either between review appointments or after discharge. Providing a robust, clear system as to how a patient can access the service either between appointments or after discharge will alleviate anxiety.

The standard melanoma clinic letter includes the following footnote (table 6) which details to both the patient and their GP the system to be followed if rapid access back to secondary care is required.

Table 6: Clinic letter footnote

| GP READ code – malignant melanoma B32 |
| GP READ code – malignant melanoma B32 |
| Alert symptoms requiring re-referral – change in skin at site of melanoma. Change in colour, shape or size of an existing mole. |
| New growing mole with or without pigment. Lymphadenopathy or organomegaly. |
| Referral to dermatology |
| If patient currently under dermatology follow up – patient to phone skin cancer link nurse to make an urgent review appointment. |
| If patient has been discharged – GP to refer urgently to dermatology |
| South East Scotland Cancer Network (SCAN) patient information - http://www.scan.ssc.tnhs.uk/CancerInformation/skin/Pages/default.aspx |

A questionnaire was sent to patients and their GPs to assess the standard melanoma clinic letter.

Table 7 Patient evaluation

<table>
<thead>
<tr>
<th>Question</th>
<th>Patient scoring N= 1 to 10 where 1 = No and 10 = Yes</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you........... find the information in the footer regarding &quot;referral to dermatology&quot; helpful?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

The majority of patients found the information within that detailed the process of referral back to dermatology helpful.

Table 8 GP evaluation

<table>
<thead>
<tr>
<th>No</th>
<th>Question</th>
<th>Patient scoring N= 1 to 10 where 1 = No and 10 = Yes</th>
<th>YES</th>
<th>NO</th>
<th>NR</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Did you........... find the information in the footer regarding &quot;referral to dermatology&quot; useful?</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>2</td>
</tr>
</tbody>
</table>
Question 8: Did you find the information in the footer regarding "referral to dermatology" useful?

GP comments:

Please add contact number incase patient has lost their copy
Most GPs found the information within the footer, that detailed the process of referral back to dermatology, helpful.

Question 10: If following melanoma discharge you required re-referral back to Dermatology did you find this process straight forward?

This question was not applicable for 85 questionnaires and in 2 cases the data was missing, for the remaining 27 the results are shown below.

Aim 3 - Rapid access system back to secondary care
Conclusions

- Continue with the current system for re-referral back to dermatology between review appointments and after discharge.
  - If patient currently under dermatology follow up – patient to phone skin cancer link nurse to make an urgent review appointment.
  - If patient has been discharged – GP to refer urgently to dermatology

- Continue to document this process within the footer of the standard melanoma letter.

- For those patients who ‘opt out’ of receiving a copy of their standard melanoma letter, consider encouraging them to take 1 copy at the time of discharge. This would ensure they have all the relevant information regarding their melanoma, management and re-referral process.
Aim 4  End of Treatment Summary

Electronic End of Treatment Summary (eEOTS) to be created for all patients and sent to their GP at the end of active treatment and / or on discharge from dermatology follow up back to primary care.

A local end of treatment summary subgroup was formed. Members of this subgroup included: Dermatology TCAT project lead, NHS Fife ehealth, SCAN Macmillan TCAT representative, representative from Fife palliative care TCAT project team, representative from Fife lung cancer team, NHS Fife cancer audit team lead, NHS Fife lead cancer GP and SCAN primary care group chair.

The group met following a Macmillan facilitated presentation by Forth Valley. The Forth valley presentation detailed different options for end of treatment summaries but in the main presented in detail a web based end of treatment summary which has been produced in Forth Valley (TSUM). The group discussed the different options available for EOTS and what would be most appropriate for NHS Fife.

Requirements for NHS Fife, a system:

- that would integrate with the systems we currently have in Fife
- which uses modern technology
- from which we would be able to produce documents that can both be stored into SCI store/clinical portal and forwarded to general practice as per other clinical letters
- that is relatively straightforward to complete which will self populate from information already known about the patient as much as possible
- which will integrate with other systems used across Scotland. Particular consideration is given to the SCAN region as Lothian are likely to utilise TRAK for production of end of treatment summaries.
- Consideration to be given to the cost of set up of the system.
- Consideration to be given to updating of the system and sharing of information with other boards and regions.

1. The first system to be considered was the forth Valley web based end of treatment summary option (TSUM). This is a system which is populated by patient information taken from SCI store. The Forth Valley System was a pilot project funded by Macmillan with the hope that it will then be adopted by other boards across Scotland. It is a generic end of treatment summary for all tumour types which becomes more specific as you enter your tumour type and other information. Much of the clinical work has already been done to produce a working document. The system is based on modern technology which is web based and talks to our back end data base. There is a national drive towards encouraging the use of end of treatment summaries and Macmillan have supported the Forth Valley system.

2. The second system to be considered is the immediate discharge document system obtained from Dumfries and Galloway. This is already used for the production of discharge summaries in hospital and palliative care. E-health do not feel that this is the desired option as it uses old technology using access as the front end and e-health specifically do not want any more access databases to be set up. In addition, the IDD system will be changing when NHS Fife move across to the use of TRAK in 2016/2017.
3. The third system to be considered is a TRAK based system producing an end of treatment summary. NHS Fife are due to move to a TRAK based system over the course of the next couple of years. The first stage in this will be the set up of a core PAS system followed by order coms. This will take approximately 2 years. Thereafter, other additional options such as the production of an end of treatment summary could be looked at. The NHS Fife system is similar to that utilised in Glasgow. E-health are unable to tell us whether this system would be able to facilitate the production of an end of treatment summary as it has reduced functionality to the system used in Lothian.

Having considered all 3 systems, it was felt that the Forth Valley web based end of treatment summary system (TSUM) would likely be the most applicable to NHS Fife. A number of meetings were had between NHS Fife ehealth and Dr Mowbray to determine the requirements for taking the work forward and the dermatology system requirements. The team from NHS Forth valley attended Fife to load the TSUM system onto an NHS computer. Unfortunately it was felt that the experience of the NHS Fife ehealth team available to work on this project was not sufficient to take it forward. NHS Fife ehealth are managing a number of developments over 2016/2017 such that resource could not be allocated to this part of our project.

An important consideration when developing an end of treatment summary is the need to communicate across regions. The majority of cancer patients in Fife are managed across Fife, SCAN and Tayside. Attempts were made by the SCAN TCAT lead to form a regional EOTS working party to take this forward at a regional level. Unfortunately we were unable to persuade Lothian to agree to join this group.

The development of an end of treatment summary for all cancer patients remains an aspiration for Macmillan and the Scottish government.

Aim 4 End of Treatment Summary

Conclusion

A standard melanoma letter was developed which details the majority of the information that would be seen in an end of treatment summary (see aim 5). The information is displayed in a structured way.

A ‘footer’ is included in all standard melanoma letters detailing information that is common to all melanoma patients. Feedback was obtained from dermatology clinical colleagues and the SCAN primary care group when constructing this letter. A ‘dictation prompt’ is visible in all dermatology clinic rooms to guide staff when dictating melanoma clinic letters.
Aim 5 – Patient “Opt In” to copy of clinic letters

This allows for enhanced communication between patient and clinicians and will enable patient empowerment.

This was discussed at the Patient Focus Group Meeting on 06/11/2014 and the feedback indicated it would be good practice.

There was a 50/50 split between those wanting a copy and those not wanting one, therefore staff can not assume that a patient will want a copy of their clinic letter. The Dr/SCLN must ask the patient their preference and document this within the standard melanoma clinic letter.

All 134 patients in the TCAT project were offered to “opt in” to receiving a copy of their clinic letters. The graph below displays patient preference:

Figure 17 “Opt in” to clinic letters

The uptake of patients “opting in” to receiving copy clinic letters was lower than expected however for patients who have “opted in” it has been well received and found to be beneficial. Due to this positive feedback it is recommended that all patients receive a copy of their clinic letters.

Standard Clinic Letter Template

As detailed in Aim 4, a standard melanoma letter was developed which details the majority of the information that would be seen in an end of treatment summary. The information is displayed in a structured way. The letter is utilised by all dermatology physicians who manage melanoma patients (consultant, speciality doctor, SCLN). (Appendix 8)

A ‘footer’ is included in all standard melanoma letters detailing information that is common to all melanoma patients. Feedback was obtained from dermatology clinical colleagues and the SCAN primary care group when constructing this letter. A ‘dictation prompt’ is visible in all dermatology clinic rooms to guide staff when dictating melanoma clinic letters.
Evaluation of standard melanoma clinic letter

In October 2016 a questionnaire with covering letter was sent to 25 randomly selected patients, who are receiving a copy of clinic letters, to evaluate how useful they found the clinic letters and feedback any suggestions of ways of making improvements. A separate questionnaire with covering letter was sent to their respective GP in order to evaluate the GPs views.

**Table 9 Response rate:**

<table>
<thead>
<tr>
<th></th>
<th>Response %</th>
<th>Response numbers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>40</td>
<td>(10/25)</td>
</tr>
<tr>
<td>GP</td>
<td>88</td>
<td>(22/25)</td>
</tr>
</tbody>
</table>

**Table 10 Patient evaluation of “opting into” clinic letters**

<table>
<thead>
<tr>
<th>Question</th>
<th>Patient scoring N= 1 to 10 where 1 = No and 10 = Yes</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Did you find it useful to receive a copy of your clinic letter?</td>
<td>1 1 1 6</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>2. Did you understand what was written in your clinic letter?</td>
<td>2 7</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>3. Did you find the subheading &quot;diagnosis&quot; useful?</td>
<td>1 1 7</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>4. Did you find the subheading &quot;management&quot; useful?</td>
<td>1 1 7</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>5. Did you find the subheading &quot;treatment aim&quot; useful?</td>
<td>1 1 6</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>6. Has receiving a copy of your clinic letter helped provide you with a</td>
<td>1 8</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>better understanding of your diagnosis and management?</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>7. Did you find the information in the footer regarding &quot;alert symptoms</td>
<td>1 1 1 5</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>requiring re-referral&quot; helpful?</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>8. Did you find the information in the footer regarding &quot;referral to</td>
<td>1 2 5</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>dermatology&quot; helpful?</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>9(a) Would you recommend to other melanoma patients that they receive a</td>
<td>9</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>copy of their clinic letter?</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>10. Is there any information you would rather not see? Yes / No</td>
<td>9</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

*1 patient stated there was no footer present on their clinic letter
**Question 9(b) – reasons to recommend receiving a copy of clinic letter:**

- It provides a much better understanding of melanoma and you can re-read it. Much better than being told
- it’s good to see it in black & white and that Consultant is happy there is nothing to worry about
- it keeps you informed of your diagnosis & treatment as sometimes it’s hard to remember everything you are told
- it provides the facts that others can read but the downside could be how these are taken
- aid to your memory because many things are discussed at the hospital. For interested patients you can do research of your own on medical terminology
- found it helpful
- reading treatment aim changed my whole perspective as it said "curative".

**Question 10 – Would you like to see any additional information in your clinic letter?**

- Everything I need to know is well detailed
- not at the moment
- reports are clear and concise
- 2 patients comments on the need for meaning of medical terms - layman’s description
- 4 patients required nothing additional.

**Table 11: GP evaluation of “opting in” clinic letters**

<table>
<thead>
<tr>
<th>No</th>
<th>Question</th>
<th>Patient scoring N= 1 to 10 where 1 = No and 10 = Yes</th>
<th>YES</th>
<th>NO</th>
<th>NR</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Did you........</td>
<td>1 2 3 4 5 6 7 8 9 10 NR</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>find the layout of the letter easy to read?</td>
<td>3 3 12 1 *</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>find the subheading &quot;diagnosis&quot; useful?</td>
<td>2 5 12</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>find the subheading &quot;management&quot; useful?</td>
<td>2 2 3 12</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>find the subheading &quot;treatment aim&quot; useful?</td>
<td>4 15</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>think melanoma patients under your care would find it useful to receive such a letter?</td>
<td>1 1 3 4 9 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>find the information in the footer detailing the GPREAD code useful?</td>
<td>1 1 4 1 4 6 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>find the information in the footer regarding &quot;alert symptoms requiring re-referral&quot; useful?</td>
<td>1 1 2 1 1 1 1 8 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>find the information in the footer regarding &quot;referral to dermatology&quot; useful?</td>
<td>1 1 3 2 2 7 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Would you like to see any additional information in this standardised melanoma clinic letter?</td>
<td>13 6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Is there any information you feel is unhelpful?</td>
<td>7 10</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Not scored but commented diagnosis section is harder to read than others and probably very hard for patients to understand
**Question 2 – Did you find the subheading “diagnosis” useful? – GP Comments:**

- Please highlight main diagnosis in bold letters
- histological type before Breslow etc
- found it very useful except when I don’t understand abbreviations (AJCC).

No comments were received for questions 3, 4 and 9

**Question 5 Do you think melanoma patients under your care would find it useful to receive such a letter? GP comments:**

- Depends on patient
- patients will be confused by diagnosis section
- some patients may struggle but most ok.

**Question 6: Did you find the information in the footer detailing the GPREAD code useful? GP comments:**

- Yes but not clear/easy to locate
- not present on clinic letter
- not scored - too small, needs to be clearer, more prominent
- yes but small to read
- no read code on letter.

**Question 7: Did you find the information in the footer regarding “alert symptoms requiring re-referral” useful? GP comments:**

- Yes but not clear/easy to locate
- don’t read small print
- hadn’t noticed this - make more obvious
- not present on clinic letter
- a further 3 GPs commented that it was too small.

**Question 8: Did you find the information in the footer regarding “referral to dermatology” useful? GP comments:**

- Please add contact number incase patient has lost their copy.

**Question 10: Is there any information you feel is unhelpful? GP comments:**

- There are too many points within the diagnosis section. Main diagnosis should be first.
**Question 11: General comments:**

- Why not use internal mail system and save on postage?
- good idea, useful letter, good standard of letter
- useful summary for GP & patient
- some patients may value this
- change headings to 1) diagnosis, 2) previous treatment, 3) management, 4) treatment aim, 5) review
- Increase font size of footer.

**Aim 5 – Patient “Opt In” to copy of clinic letters**

**Conclusions and actions**

- The majority of patients found the standard melanoma clinic letter and all subheadings included within this useful.
- The majority of patients would recommend the standard melanoma letter to other patients.
- No additional information was requested by patients.
- The majority of GPs found the standard melanoma clinic letter and all subheadings included within this useful.
- No additional information was requested by GPs.
- No information was regarded by GPs as ‘not useful’.
- GPs requested that abbreviations should not be used. AJCC, WLE, SLNB to be written out in full.
- GPs requested main diagnosis to be highlighted. Melanoma, site and date of diagnosis to be highlighted in bold.
- Melanoma diagnosis to be listed first.
- Some GPs felt that patients may be confused by letter and diagnosis section. This was not reflected in comments from the patients. Structure of letter to be kept the same.
- In general GPs felt the footer to be helpful but too small. To look at increasing size of footer information without making letter too long.
- Contact number of dSCLN to be added to letter.
- At the initial patient focus group meeting the uptake of patients “opting in” to receiving copy clinic letters was lower than expected. The decision was made to offer patients the choice to ‘opt in’ to receiving a copy. For patients who have “opted in” it has been well received and found to be beneficial.
- Due to this positive feedback it is recommended that all patients receive a copy of their clinic letters from now on, this will be discussed with consultant colleagues.
Aim 6 – Patient Self Management

One of the objectives of the NHS Fife TCAT project was to set up self management workshops to allow patients the opportunity for psychological support and an education programme.

Self management groups were discussed at the Patient Focus Group Meeting on 06/11/2014 and the concept was well received.

A melanoma workshop subgroup was set up. The subgroup was attended by NHS Fife TCAT members, Alison Harrow Head of Maggie’s, Alison Watt phase 2 TCAT Project Manager for the Local Authority, SCAN and Macmillan representatives. The programme was designed to take into account feedback from the patient focus group. The programme was designed to use staff from within Maggie’s, NHS Fife and Fife social care. This should allow the workshops to be continued longterm without the requirement for recurrent funding. All patients diagnosed within the previous 5 years were to be invited to a workshop therefore 5 workshops spread over a 1 year period were required. Due to space only 12 attendees could be accommodated at a time, partners/carers could not be invited to the workshop but were welcome to sit round the kitchen table and have tea/coffee.

All patients were given a bag containing programme information, Maggie’s information and sunscreen. Ian Stone, patient representative, kindly contacted different sunscreen manufacturers to arrange sponsorship of the melanoma workshop by way of sunscreen samples.

An example of the programme is seen below. Members of each team gave a presentation and all teams were represented including: Maggie’s, dermatology consultant, a dermatology and plastic surgery skin cancer link nurse, a local area co-ordinator and the project patient representative Ian Stone.

Melanoma workshop programme

- Partnering your medical team – consultant dermatologist (skin examination card Appendix 10)
- Emotional wellbeing – Maggie’s psychologist
- Advice about benefits – Maggie’s benefits advisor
- Community Connections – How Fife Council can support you – phase 2 TCAT project manager
- Where now? – Head of Maggie’s centre
- Kitchen table informal discussion – tea and coffee

The workshops took place in Maggie’s at Victoria Hospital. There were a total of 5 workshops.

Table 12: Melanoma Workshops

<table>
<thead>
<tr>
<th>Date of Workshop</th>
<th>No of invitees</th>
<th>No of attendees</th>
<th>No of questionnaires completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>08/04/2016</td>
<td>20</td>
<td>9</td>
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<tr>
<td>29/04/2016</td>
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<tr>
<td>24/06/2016</td>
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<tr>
<td>09/09/2016</td>
<td>41 for both</td>
<td>6</td>
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</tr>
<tr>
<td>04/11/2016</td>
<td>As above</td>
<td>6</td>
<td>4</td>
</tr>
</tbody>
</table>

Melanoma Workshop Feedback analysis
Patients who attended were asked to complete an evaluation questionnaire at the end of the programme. The workshops have been well received and are now built into the patients care plan. A small sample of the patient feedback is detailed below and the full evaluation of the questionnaire can be found in appendix 9.

**How would you describe the workshop to a friend?**

The word cloud below shows the words used by patients to describe the workshop, the bigger a word appears on the cloud, the more frequently it was mentioned by patients.

![Word Cloud]

**How confident are you that you can manage your condition by yourself?** Eg carry out a self examination of your skin, to recognize a worrying/changing skin lesion, use of sun protection, what to do if you are worried about a change in your skin etc
In what ways do you think we could improve the workshop?

**Roll out the workshop to other areas- “take it on the road”**
- Workshop available in most council areas

**More interactive session - sharing.**
- More opportunity to discuss with fellow patients / more interaction with other patients

Any other comments?

- really enjoyed the workshop, and thank you!
- good to have time to meet others and be able to find out about support available
- disappointed their link nurse wasn’t present
Aim 6 – Patient Self Management

Conclusions

• The workshops were well received by patients who found them informative, helpful, interesting, worthwhile and friendly.

• The most appropriate time point to invite a patient to a workshop is approximately 5 months post diagnosis after their active treatment has been completed.

• The long term aim would be to have 3 workshops per year and for attendance to be regarded as a standard component of the melanoma patient pathway. Patients can be given a date for attendance and sent a reminder letter nearer the time.

• Attendance at the melanoma workshop is documented on the standard melanoma clinic letter and can be documented in the ‘patient plan’. This will make all consultants aware of whether their patient has received an invite.

• All aspects of the programme were well received.

• Additional content to be considered
  
  o Advice about travel insurance after a melanoma diagnosis
  o Reference to children, for all people with melanoma there will be a child involved (children, grandchildren)
  o Enable more facilitated discussion around the coffee table after the formal programme. Invite patients to tell their own story
  o Within the ‘partnering your medical team’ section, include a plastic surgery bank of images of various conditions and outcomes to show patients eg skin graft, donor area

• Using Maggie’s as a venue for the workshop was welcomed. This allowed melanoma patients exposure to Maggie’s and the services on offer. Workshop to be continued to be offered out of Maggie’s.

• The timing of the workshops, Friday afternoon, suited most people (patients and staff).

• Maggie’s centre is in Kirkcaldy. Consideration should be given to the cost of travel for those coming from Dunfermline. SCLN to source information re travel options eg volunteer drivers.
The Transforming Care After Treatment programme has had a strong focus on User Involvement demonstrated by the creation of the TCAT Patient Experience Panel. Each project was expected to seek the views of patients/carers and also involve them in the reporting structure to inform and drive change from real experiences.

In Fife all 3 TCAT projects have one patient/carer representative sitting within the operational panel and also representation at the joint steering group. As the 3 Fife TCAT projects have been separate entities, it felt important to connect the patient and carer representatives through a separate forum so that they were not working in isolation and to explore how the patient/carer role could be co-ordinated in Fife to be more meaningful to the individuals. The Fife TCAT Patient Reference Group evolved from this early thinking with the prime purpose of gaining a true perspective on the cancer journey of people affected by cancer and to understand if TCAT made a difference to the individuals.

The Reference group consists of 3 patient/carer representatives from each of the TCAT projects in Fife, TCAT User Involvement Manager, TCAT Phase 2 Project Manager and Local Area Co-ordinator (LAC). The initial Patient Reference Group discussions centred on developing forums for patients who were part of the TCAT projects in Fife to gain feedback about their experiences. Common themes would then be fed back to the relevant 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 Malzer. From the early meetings it was clear that the Patient/Carer representatives were keen to take a proactive role and have a meaningful input into the TCAT projects. The group wanted to gather feedback from people who were going through their cancer journey now and were experiencing the improved cancer pathway through TCAT. It was thought the information gathered could then be fed back to the projects and could help inform and enhance future service development.

Peer to peer model of engagement

Initially it was thought that focus groups could be set up to engage with service users from the projects but numbers were small therefore the group decided that individuals affected by cancer who wanted to talk about their cancer journey could talk to a patient/carer representative on a more informal and relaxed peer to peer basis. It was further agreed that a Local Area Co-ordinator from the phase 2 TCAT project would also be involved in the peer to peer meetings to co-ordinate and record the sessions but also offer support to the person attending the session and the patient/carer representative. These measures were agreed to safeguard those involved and comply with data protection legislation. The location of the peer to peer sessions was also thought to be important and the group negotiated a safe location for the meetings at Maggie’s Centre in Kirkcaldy. Maggie’s centre had agreed to hold the collected information and also offer additional support from qualified staff at the centre if required by any party involved in the sessions.

The information gathered at the sessions is analysed by the phase 2 team with the patient/carer representative to look at common themes and then the common themes are then fed back to the relevant project/service. It was known that the proposed peer to peer sessions would not be accessible to all people affected by cancer especially those who were too unwell to be able to leave their homes. After negotiation with the TCAT strategic group it was agreed that the peer to peer model could be extended into individuals homes with LAC participation but there have been few who have been well enough to take up this option.
Ian Stone has been working with the TCAT Melanoma project from an early stage. His involvement started with attendance at a focus group that was held for patients with a melanoma diagnosis. The focus group were asked about their experiences, positive or negative, and this information was used to shape the development of the melanoma project. Ian became more involved in shaping the project when he then sat on the operational steering group for the TCAT melanoma project.

Ian joined the TCAT Reference Group and has been involved in developing a working model for peer to peer meetings in Fife. Patients signed up to the peer to peer sessions at Melanoma workshops that were organised through the TCAT Melanoma project. Staff from the Phase 2 TCAT project organised the peer to peer sessions at safe and local venues so that there was flexibility for individuals attending the sessions. Ian has now conducted 9 peer to peer sessions with Sharon Breeze, LAC. The sessions usually start with Ian sharing his own cancer journey, followed by the individual who is attending the session sharing their own experience on what has gone well, what has not gone so well and what could be improved. Sharon sits on the side lines and scribes the session with permission for the participant.

Quote from Ian (Patient Representative from the TCAT Reference Group)
“I personally found the "Peer to Peer" interviews daunting but very rewarding. Initially, I thought they were about just gaining information to improve the Melanoma process, but I soon found out that wasn't the case. They also gave an opportunity to the patient to discuss concerns or issues in a safe environment that they may not have been able to discuss with their family and / or the NHS. The majority of the patients I interviewed were very supportive of the "Melanoma Workshops" which were run over the previous 12 months after a lot of effort to arrange by Dr Megan Mowbray and her TCAT team."

Quote from Sharon (LAC from the TCAT Reference Group/Phase 2 project)
“Arranging and facilitating the peer support sessions has been a part of my role as a Local Area Coordinator with TCAT. I have enjoyed working with the patient representatives and supporting them to gather patient stories which are currently being used to transform the way care and treatment is delivered. Knowing that the information gathered is being used in a positive way has made this area of work so rewarding and I believe that the people in receipt of cancer services are very well placed to influence positive changes in the process by sharing their experiences”.

Melanoma Peer to Peer session findings

To date there have been 9 peer to peer meetings completed for people with a melanoma diagnosis with potential for more to be planned. The 9 participants of the sessions have all given permission to feedback their experiences anonymously to the Melanoma Project to help shape the service further. The information from these sessions has been fed back in a number of ways to the Melanoma team. The main themes to come out of the peer to peer meetings are as follows and have been linked to some of the aims of the project;

Aim 1 – Pathway
Evidence of pathway development and people feel supported and confident about the pathway as these quotes demonstrate;
“Being given a folder full of information was excellent and really helped me through the process”
“Everything was really quick and efficient and being reviewed 3 monthly in clinic is very reassuring”
• Inconsistency of GP referral to the Dermatology Consultant
• Insufficient medical advice about the decision to have lymph node biopsy or not – causing worry to half patients who had peer to peer meetings.
• Limited knowledge on the timing of different parts of the pathway and therefore unsure of the expectations. This has now been addressed in a flowchart which is given to patients.
• Not always clear communication given about diagnosis at clinic. 2 individuals did not know they had cancer until they researched the terminology or were given Macmillan information.

Aim 6 – Link Nurse Clinic

• 6/9 people were happy to attend the nurse led clinics as they felt that the nurses were knowledgeable and had a level of expertise. They reported that they did not mind that they don’t see the Consultant at every clinic. One person felt their answers were not answered or a plan set to come back to them. 2 individuals did not specifically comment on the role of the link worker but reported their treatment was excellent from all staff involved.

Aim 7 – Melanoma Workshops/Peer to Peer sessions

“I really enjoyed the workshop and felt that it was good to speak to other people who had been through the same experience”

“I felt that attending the workshop was a very positive experience as people who attend the workshops are able to share the information with family and friends and raise awareness of skin cancer”

• 9/9 people enjoyed the Melanoma workshops and liked to connect with people who had gone through a similar experience. They also reported that they liked to hear each other’s stories. One person reported that they did not get much out of the workshop because the group members were older.
• 2/9 specifically reported that they liked the laminated skin checking sheet and the information on sun protection which were given out at the workshop.
• 9/9 people reported that they really valued and enjoyed the peer to peer sessions. They reported that they found it useful talking to someone who had gone through their own cancer journey.
• 5/9 people stated that they would not have shared some of their thoughts about their cancer experience with medical staff but were happy to share their experiences in the peer to peer meetings.
• 9/9 people from the peer to peer meetings reported that they found the information that they received at the Melanoma Workshops useful and valuable.

Over all the feedback from participants of the peer to peer sessions and the Melanoma Workshops was very positive as demonstrated in the quotes below;

“I really enjoyed the peer support session and felt it was very positive to be able to talk things through with someone who had been through the same process”
“I felt that the peer support session was fantastic. I enjoyed talking to someone who had been through the same thing and sharing my experience”.
“I really enjoyed the peer support session and feel it was a very positive experience to be able to talk things through”
It is clear that patients who have attended the workshop enjoyed sharing their experiences with a person who has been through a similar journey, reporting that they found it informative and offered them an impartial person to talk to with a route to feedback their experiences whether they were positive of not.

The 3 main points to come from the 9 Peer to Peer sessions are;

- Evidence that the patients who attended the Melanoma Workshops found them enjoyable and valuable. Patient’s reported feeling supported and informed.

- Patients were very positive about the treatment they received from the Dermatology Service but would value more assistance in making treatment decisions such as the decision to have a lymph node biopsy or not.

- Patients are keen to see better communication between GP’s and the Dermatology Service to smooth the pathway more and also would like to see the use of language which is easy to understand to offer clarity regarding their diagnosis and prognosis.

**Future peer to peer working**

The Melanoma team hope to continue offering the Melanoma Workshops to patients which in turn offers an opportunity to continue the peer to peer work with this patient group. The feedback from individuals who have used the peer to peer sessions has been very positive which demonstrates the value of this approach as a reflective feedback mechanism for services to help shape future the cancer care pathway. The TCAT Reference Group have developed a peer to peer model of engagement through the work undertaken within the Fife TCAT projects which the group hope to extend to other cancer groups and organisations.
Quotes from the individuals who attended the peer to peer meetings.

Pathway - GP Stage

“I had an appointment with my GP regarding a mole which had gone pink. I was referred immediately to the Dermatology Consultant and was seen within a month”.

“I had 3 appointments within a 10 month period with my GP and was told there was nothing to worry about and sent away”

Dermatology Process

“The whole process was smooth and timely and I felt supported through the pathway. I felt that the experience was positive and the support was there for me”

“Everything happened quickly from the first appointment with the Consultant at the Victoria Hospital, Kirkcaldy”

“I feel reassured by the regular follow ups with both the Link Nurse and the Consultant”

“I signed the consent form to opt in to receive copies of letters to my GP but no letters have been received”

“I felt that I had to wait a long time to get results following the wide local excision and nobody suggested that I take anyone with me to get the news that it was malignant”

“I felt that 6 weeks was a long time to wait for the results of the wide local excision”

“The regular reviews in clinic and easy access to the clinic if I have any concerns are really positive”

“I opted to have a wide local excision rather than a sentinel node biopsy but I would have liked more advice about which one to opt for”
Communication

“Nobody told me I had cancer. The word melanoma was used in clinic and I had to go home and look it up online to find out what it meant”.

“I had an appointment with the Link Nurse who gave me a pack with the word “Maccmillian” on it. I felt shocked when I saw it and had trouble listening during the rest of the appointment.”

“I had an appointment with the Link Nurse but I could not get answers to the questions I raised and left the clinic feeling very stressed”.

“I felt that the Link Nurse was really good and had all the answers to my questions”

“The Link Nurse was very good and I found her really easy to talk to at my appointment”

Links with Plastics

“I had a wasted appointment with Plastics as the results had not been uploaded onto the computer system”.

“I would have liked the Link Nurse to keep in touch with me during the time I was under the care of the Plastics Team”
Melanoma Workshop

“I felt that attending the workshop was a very positive experience as people who attend the workshops are able to share the information with family and friends and raise awareness of skin cancer”

“I felt that the workshop was really useful for giving information about sun protection and skin checking. It was an interesting and supportive environment”

“I enjoyed attending the workshop and found the information useful”.

Peer Support Sessions

“I really enjoyed the peer support session and felt it was very positive to be able to talk things through with someone who had been through the same process”

“I felt that the peer support session was fantastic. I enjoyed talking to someone who had been through the same thing and sharing my experience”.
Actions following peer to peer review outcomes

- All patients will be given a folder at the time of their melanoma diagnosis. The folder will be used to file all paperwork given to the patient regarding their melanoma. Clinic letter copies and photographs can also be stored in this folder. The personal plan will be filed at the front of this folder. The patient will be asked to take the folder with them to all appointments – dermatology, plastics, oncology, GP.

- The south East Scotland Cancer Network Skin Group (SCAN) have detailed on their workplan the need to update the current SLNB information leaflet so as to aid decision making for patients.

- Occasionally a patient had concerns regarding their pathway from GP diagnosis and referral to first hospital appointment. This part of the pathway is outwith the realms of this project. It is hoped that the introduction of the standard melanoma clinic letter will highlight the importance to GPs of the melanoma patient pathway, highlight important prognostic and management factors, detail support services available and generally increase awareness of appropriate management. Dr Mowbray has secured funding for a ‘detect cancer early’ project which will focus on the recognition of benign and malignant skin lesions by GPs and appropriate management/referral of these lesions.

- As part of the DCE project the ‘laminated skin check’ leaflet will be printed in bulk and made available to patients, the public and GPs.

- Melanoma follow up alternating between dermatology consultant and dermatology SCLN will continue. Recurrent funding has been agreed for this.

- The melanoma workshop will continue with 3 dates agreed for 2017. The workshop will be held in Maggie’s Fife.

- Communication whereby patients are able to ‘tell their story’ will be facilitated round the kitchen table at the next workshop.

- The Phase 3 plastic surgery SCLN project will address the need for patients to be informed of their WLE and SLNB results in a timely manner.

- The Phase 3 plastic surgery SCLN will ensure there is no gap in support during the 5 month period that a patient is under the care of the plastic surgery team.

- The methods for rapid access back into dermatology between clinic appointments and after discharge will continue.
<table>
<thead>
<tr>
<th>Action</th>
<th>Progress</th>
</tr>
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<tbody>
<tr>
<td>Update colleagues regarding outcomes/actions from TCAT</td>
<td>Complete.</td>
</tr>
<tr>
<td>Disseminate findings – local, regional, National, International, assist with Scottish Government Melanoma QPIs review</td>
<td>Ongoing. Following 3 years QPI data the revised Melanoma QPI publish date is June 2018.</td>
</tr>
<tr>
<td>Determine the future of the Directory of Services – local, regional, national</td>
<td>To be completed.</td>
</tr>
<tr>
<td>Melanoma workshop – ongoing, development of programme.</td>
<td>Permanent fixture in the melanoma care pathway – dates for 2017 have been agreed.</td>
</tr>
<tr>
<td>Peer to peer review sessions</td>
<td>to continue at present.</td>
</tr>
<tr>
<td>Dermatology SCLN clinic</td>
<td>permanent funding agreed and dSCLN clinic continues to run weekly at each site.</td>
</tr>
<tr>
<td>Dermatology SCLN to mirror plastics SCLN with electronic documentation of phone call contact with melanoma patients.</td>
<td>To be completed.</td>
</tr>
<tr>
<td>Personal folder for all melanoma patients – to include: personal plan, all info given, photographs, copies of standard melanoma clinic letter.</td>
<td>Ongoing in dermatology. Plastics Phase 3 TCAT project are aware of the personal folder and will encourage patients to bring it to Plastic clinic appointments.</td>
</tr>
<tr>
<td>Development of examination cards as used in melanoma workshop, to be used across Fife.</td>
<td>To be made available to GP practices as health promotion for Melanoma Detect Cancer Early initiative. To be distributed on Fife beaches during the summer.</td>
</tr>
<tr>
<td>Detect cancer early project – focus on GP recognition and appropriate management of benign and malignant skin lesions.</td>
<td>Steering Group created and project development has commenced.</td>
</tr>
<tr>
<td>The south East Scotland Cancer Network Skin Group (SCAN) to update the current SLNB information leaflet so as to aid decision making for patients.</td>
<td>Ongoing as part of plastics phase II project.</td>
</tr>
<tr>
<td>Sun protection notices to be erected at all Fife beaches</td>
<td>TCAT Patient Representative secured funding for notices to raise awareness to the public.</td>
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</table>
Appendices

Appendix 1

ICCC Project Details - Engagement and Participation within TCAT

Background;
When the Phase 2 TCAT project started in July 2015, Sandra Bagnall and Simon Malzer started to look at ways to bring all 3 Fife patient/carer representatives together to make sure they had contact together so they were not working in isolation, to explore how user involvement could be co-ordinated in Fife and to ensure the role of the patient/carer representative was developing into a meaningful role. The Fife TCAT Patient Reference Group evolved from this early work.

The initial discussions centred around developing forums for patients who were part of the TCAT projects in Fife to gain feedback about their experiences. Common themes would then be fed back to the relevant 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 Malzer. As the phase 2 project has become operational there have been very few referrals from the phase 1 projects due to patients being too unwell or did not require the service but other referral routes are providing potential avenues for feedback and this has not altered the working dynamic of the group. The Project Manager and one Local Area Co-ordinator of the Phase 2 project are part of the core group alongside Simon and the Patient/Carer Representatives from each TCAT project in Fife.

Planning;
From the early meetings it was clear that the Patient/Carer representatives were keen to take a proactive role and have a meaningful input into the TCAT projects. The group wanted to gather feedback from people who were going through their cancer journey now and were experiencing the improved cancer pathway through TCAT. It was thought the information gathered could then be fed back to the projects and could help inform and enhance future service development. At this point we planned to organise focus groups but numbers were small so interviews were planned where individuals who wanted to talk about their cancer journey could talk to the patient/carer representatives on a more informal and relaxed peer to peer basis. Any common themes coming out of these meetings would be brought back to the Reference group so this information could be reported back to the relevant project.

A lot of planning work and partnership working has been undertaken by the TCAT Patient Reference Group to develop a model of peer to peer work. We have established links with Maggie’s; Fife Voluntary Action and Fife NHS Patient Relations Team to establish an effective route to participation and engagement.

Safe Guards;
As part of the development of the TCAT Patient Reference Group several safe guards have been put in place.

- A Terms of Reference has been drawn up for the group with a process of peer to peer interviewing.
- Maggie’s have agreed to work in partnership with the TCAT Patient Reference Group to support the sessions offered. The sessions have been limited to Maggie’s Centre in Kirkcaldy. Other venues in Fife will be considered to offer flexibility to the sessions but these will be arranged and supported by the Local Area Co-ordinator or Project Manager.
• Kirkcaldy Maggie’s Centre was considered to offer a warm and informal environment with professional support for everyone involved in the peer to peer sessions. The Maggie’s centre can also offer storage of information to ensure data protection.

• A peer to peer interview will only take place with the full consent of the individual and the knowledge of how the information given will be used.

Our progress to date;

The group have conducted 3 peer to peer interviews to date. We have tried to keep the sessions flexible but this has resulted in the sessions happening away from Maggie’s due to frailty and lack of space on the chosen day.

Every effort will be made to hold the sessions at Maggie’s in Kirkcaldy but the group has agreed the sessions need to be flexible to locality and timing. The safe guard to assist the flexibility of this approach is to have the Local Area Co-ordinator to attend the peer to peer sessions as a note taker.

Generally points from the sessions are as follows;

• Each person that has been involved in the peer to peer sessions has reported that they find the experience positive.
• The sessions have been informal and friendly.
• The individuals taking part in the sessions understood the reason why the peer to peer sessions are taking place and gave their consent for the information to be feedback into the respective projects.
• There has been feedback that the individuals feel more able to speak freely about their experiences.
• Most of the individuals who have requested a peer to peer meeting have come from the Melanoma Workshops as the process has been discussed and offered to participants. Individuals have been keen to engage in sharing their experiences with potential to help shape services

Points to consider;

• The development time of this area of work has taken a year from the first meeting because the Phase 2 project was only just beginning to take shape when the early discussions took place and also putting the safe guards in place which has frustrated the Patient/Carer Representatives.
• There are many people who cannot attend Maggie’s to be able to connect to the current peer to peer meetings that have been set up and therefore there are individuals who are unable to share their cancer journey and experiences.
• The focus groups that were first discussed have not developed due to lack of numbers. This would include a carers group where individuals can share their experiences together and offer feedback about the TCAT projects.
• Training for the Patient/Carer Representatives
• Funding for PVG or being part of a volunteer programme
• As at September 2016 local authority had received in excess of 90 referrals mainly from social work contact centre.
• People are engaging in this process and meetings are sometimes lengthy and can last 2½ hours.
• Sustainability of this line of work out with TCAT
Questions/points to consider;

- How do we connect with individuals who cannot leave their homes, whilst preserving the emerging benefits of the peer to peer approach to feedback gathering?
- How can we enable the Patient/Carer representatives develop their role?
- How does this work continue when TCAT Phase 2 ends?
- Can we connect to other work surrounding Participation and Engagement?
- LAC funding will hopefully continue post TCAT
- Consider future proofing of Directory of services post TCAT

As a result of cross over with between NHS Fife Melanoma phase I project and Local Authority/Social Care phase II TCAT project a Directory of services has been developed from Holistic Needs Assessment concerns and will be updated every 6 months with consultation with SCLN prior to issue. The first Fife TCAT newsletter has been produced and distributed. A contribution was made from all 3 projects.
Appendix 2

Welcome to the First Transforming Care After Treatment (TCAT) Pilot Newsletter. Our aim is to keep you updated on how each of the 3 projects in Fife are progressing.

The Fife TCAT Story So Far.........

Macmillan Cancer Support has funded 3 TCAT projects in Fife. All 3 projects are working together and in partnership with associated services with the aim to improve the cancer journey for individuals in Fife.

Here’s the story so far......

Best Supportive Care TCAT Lung Project

Lung cancer pathways were not defined and there was no consensus about what constitutes best supportive care and who should deliver it.

This pilot aims to assess the feasibility and impact of early, streamlined palliative care and improved integration and coordination of care.

In the first year of the project we have developed and successfully implemented a robust pathway with over 200 patients and their families experiencing the enhanced service.

In the final 6 months, work will focus on more effective sharing of information and care coordination with Fife Council’s TCAT Project, as well as evaluating the impact of the project using a range of methods including patient and family feedback through interviews and surveys.

The project aims to sustain the elements of the new service which improve the quality of care and experience for patients and their families. The resources required for this are being identified.

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TCAT Dermatology Melanoma Project

The melanoma TCAT project in Fife aims to develop support for melanoma skin cancer patients. This is being achieved by:

- Developing the role of the dermatology and plastic surgery Skin Cancer Liaison Nurses
- Developing an electronic treatment summary for patients
- Providing melanoma patients a copy of their clinic letter
- Development of a melanoma workshop based at St. Margaret’s House.

We hope to enhance awareness of the support that is available from Macmillan, Dermatology and Fife Social Care. Education with regards to self-examination and sun protection will be included in the clinic letter. The workshop will provide a supportive environment for melanoma patients and their families.

"The TCAT Skin Cancer project is currently transforming the way melanoma patients are treated within the NHS in Fife. By providing ongoing support and education, we hope to improve patient outcomes and make your journey feel less daunting.

My name is [Name], and I am a [Profession] at [Hospital]. I am here to help you with your [specific needs or concerns].

---

Integrated Community Cancer Care Project

Meet our new Local Area Coordinators

Giuliana Borghi

Vicky Green

Integrated Community Cancer Care (ICCC) is the reveal of the three Fife TCAT projects. Our focus is to connect individuals who have recently finished cancer treatment in our Local Area Coordinators, Sharon and Barry. Their role is to enhance the patient and carer journey after diagnosis. Their work will help develop local networks to provide ongoing support.

ICCC links directly with TCAT’s Lung and Melanoma projects along with other cancer types.

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Helping people affected by cancer to move more

A cancer diagnosis and treatment can make you feel tired and weak. It can also leave you with little energy and feeling low. The advice used to be that rest was best, however research shows that moving is one of the best ways to help you feel better.

Macmillan Move More File is a programme of activity specifically designed for people affected by cancer. From gentle stretching to more vigorous programmes, there is something for everyone. All activities are free of charge and you'll be with others that know exactly what you are going through.

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## Appendix 3

### NHS Fife Melanoma TCAT Project

#### Pro Forma

Please attach a label

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### Details

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<thead>
<tr>
<th>Diagnosis Date</th>
<th>Date 1st attended TCAT Project</th>
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**Holistic Needs Assessment**

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### Follow up

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<th>(✓) Appointment with Skin Cancer Link Nurse</th>
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### Additional Information

|                          |                                |                                            |
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|                          |                                |                                            |

### ECOG Performance Status

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<tr>
<td>1</td>
<td>Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work</td>
</tr>
<tr>
<td>2</td>
<td>Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours</td>
</tr>
<tr>
<td>3</td>
<td>Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours</td>
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<tr>
<td>4</td>
<td>Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair</td>
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<td>5</td>
<td>Dead</td>
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Appendix 4

Dermatology Focus Group Discussion

NHS Fife Dermatology Transforming Care after Treatment Group (TCAT) held a focus group discussion in November 2014 involving patients and carers who had received a diagnosis of melanoma. Through the focus groups, the dermatology team gathered information to help inform clinical staff how to develop this service further in response to patients needs.

Introduction:
The dermatology TCAT team held a focus group discussion with patients and carers on the 6th November 2014. The focus group was conducted as part of Dermatology’s service development through the TCAT work-stream. Participants provided information through group discussion.

The discussion was designed to gather information from the participants in relation to the following outcomes:

1. To understand what happens when a patient receives a diagnosis.
2. To understand the level of support required by patients.
3. To understand how patients and carers perceive NHS Fife’s effectiveness in meeting their needs.
4. To understand what impact responsibilities outside of health have on a patient and their family when living with cancer.
5. To understand the importance of psychological and social support in helping patients and their families cope with living with cancer.

20 participants took part in the focus group. 15 were women and 5 were men. 16 were patients and 4 were carers. The participants were divided into 3 groups, each with a facilitator and scribe. Each facilitator followed a format developed to elicit insight into the outcomes listed above.

Participants perspective:

Outcome 1: To understand what happens when a patient receives a diagnosis

All participants were invited to recount their diagnosis if they wished. All participants without exception described the immense shock at being told of their diagnosis. Some participant responses are included below:

- Shocked- floored-can’t remember driving home.
- Such a shock – had to go home after diagnosis as really shocked.
- I thought struth your dead! Had my chips…..
- Didn’t take it in, thought I was preparing for my funeral….
- Remember asking, what is melanoma?
- Doctor phoned and said “you’ve got cancer”.
- Why us?
• It didn’t hit home until I spoke with the skin cancer link nurse.
• Quick appointments cause alarm.
• Best have someone with you for extra support.
• Need time to come to terms with diagnosis.
• MEDINET (waiting list initiative clinic) – extended timescale from referral to appointment and results causes distress.
• Would have been more beneficial to receive written information at consultation.
• Internet is dangerous, carried out a lot of research.
• Discuss how patient would like to be informed of their results, ask before/at time of investigation – by phone, in clinic.
• Attended clinic alone, felt isolated.
• Advise that patients are ‘welcome’ to bring someone with them.
• Driving after receiving results could be dangerous.

Within the focus group it was apparent that there were numerous ways patients receive their diagnosis the majority were informed by the dermatologist and some by GP.

What all patients recognised was they need time to discuss their diagnosis, but there is not a one “fit” for all. It was suggested that patients should be offered a choice of how to get the results of investigations which lead to a diagnosis - either at home (phone) or at hospital.

Most patients spoke about the extended timescale from referral, to appointments and results as a period in their life when anxiety and distress was raised. Conversely some of the participants recalled quick appointments which were a cause of alarm in themselves and a quick diagnosis does not allow for time to start coming to terms with the diagnosis.

In order to structure this around clinical service delivery direct discussions were had regarding specific aspects of the TCAT; Holistic needs assessment (HNA)

When is the optimal time to undertake an HNA – after surgery +/- SLNB?

What the focus group told us was there needs to be flexibility in the system, and there is not a one size fits all, we need to discuss and agree with the patient in their treatment plan when is the right time for them to have the HNA undertaken. Patients highlighted the importance and the necessity of not only needing but wanting time to talk about the impact of their diagnosis.

Outcome 2: To understand the level of support required

Direct discussions were had about accessing the service between appointments or after discharge, this is what patients and their families told us:

• GP wouldn’t know, I was dealt with by hospital – brilliant.
• I would phone Elaine – she gave us a card – we look for any changes in moles.
• I would phone Lynn.
• I would wait until appt with Doctor – don’t want to ring all the time.
• Go to someone you know better and who knows you – link nurse.
• GP doesn’t see enough lesions – should be trained better.
• GP would recognise it straight away.
• It is good to know what to do in between clinic appointments.
• Lump on scar, scared until seen and checked.
I’m concerned as my last appointment is coming up. Makes me wary.

All participants spoke positively about the support the skin cancer link nurse provided to them (Elaine, Gail, Lynn, Carol).

- ‘Link nurse’ is a nice word (inclusive).
- Elaine was great…
- Nurse explained…. didn’t throw punches, made tea, settled me down….
- Sent to Elaine for more information.
- Was given a name, telephone no, named person who you’ve met.
- Skin cancer link nurse process is right.
- Skin cancer link nurse (Lynn) gave telephone number to contact her.
- At appointment need time for questions.
- Need to know who to contact.
- It is reassuring seeing the same person.
- Accessing internet can cause extra stress.

Experience for partner/family:

- Shock, worry, father was same age, talked more to daughter, kept a lot to myself, thought this was it.
- 11 year old daughter associated cancer with dying.
- We had no secrets but kept it limited- reassurance given and accepted by daughter.
- Daughter asked questions and I didn’t have the answers. We only got the big picture, not the ins and outs.
- There should be something for children to help them understand – explain it to them.
- Children need to understand and be educated.
- Damage is caused when you are young.

It was helpful to have a contact number. However, the level of written information provided is not always what the patient requires.

“Cancer- what is melanoma? - no literatures given until visit to Dundee….would have been more beneficial to receive written information at consultation”.

Your mind goes mental… GP couldn’t answer questions but Lynn and consultant could”.

Leaflets: Macmillan melanoma booklet most helpful, SCAN melanoma leaflet also given out including contact details for skin cancer link nurse.

One group specifically intimated that relatives need support as well.

Our practice should be linked to lowering anxiety including:

1. Preparing the patient for a possible diagnosis of cancer.
2. Having the people wanted by the patient present to hear the diagnosis.
3. Giving the patient as much information about the diagnosis as desired.
4. Providing written information; presenting the information clearly.
5. Discussing the patient’s questions as they arise.
6. Talking about the patient’s feelings; and being reassuring. Discussing the severity of the situation, and how the cancer might affect other aspects of life.
7. Encouraging the patient to be involved in treatment decisions.

A diagnosis of cancer is a very stressful event for the patients and their families. Clinicians need to be family-focused as cancer affects the whole family, not just the patient.

Outcome 3: To understand how patients and carers perceive NHS Fife’s effectiveness in meeting their needs

- Ninewells Hospital – operation, experience unbelievable. No faults with service.
- There was a difference in dressings advice between ward nurse at discharge (3 days) and plastic surgeon at clinic (10 days). Phoned skin cancer link nurse for clarification. Note - this occurred when plastic surgery was provided in Livingston, it is now provided by Tayside.
- Photographs taken – consultant checks, difficult for patient to make sense of. Wife takes over this role.
- Good to be checked up.
- Full skin examination is very reassuring.
- At the end of contact with plastic surgery all patients felt they had received enough information.
- I am now more aware of examining my partner/relatives.
- It was felt that consultants don’t have time to discuss social issues.

Direct discussions were had regarding specific aspects of the TCAT project

- Copy of clinic letter for patient

This is what patients told us:

- Yes, I would like to be included.
- Relieves anxiety – good idea.
- We would have panicked if we had seen it written in a letter.
- Any information is good at least you can discuss contents of letter.
- Going to GP initially - not kept in the loop.
- I’ve found out about things today I didn’t know.
- I couldn’t understand it – I had nothing on the skin maybe I would have understood it if I had seen it written in a letter.
- This would be helpful.
- Mix between those who felt this would be helpful or not, some relatives felt it would be helpful, eg husband as always at work at time of clinic appointment.
- Follow up timescales were given verbally.

As you can read from the above all the quotes with the exception of one indicate this would be good practice. However, it is ultimately a patient decision therefore a discussion needs to be held between clinician and patient.
Direct discussions were had regarding Nurse led clinics:

- Wouldn’t bother me attending – good service.
- What authority would they have? to remove lesion etc.
- Everything gets checked properly.
- Variation in examinations, some thorough, some not.
- Dr always meets expectations - I see same one.
- Appointment with link nurse to discuss general well being would be good.
- Would welcome alternate out patient appointments with consultant/skin cancer link nurse.
- I would still want the consultant to examine my skin.

There is growing evidence indicating that ‘quality of life assessment’ can be considered as adjuvant to clinical and physiological assessments in many chronic conditions, particularly cancer. The participants share with us the type of needs which need further attention.

- Know what to do between appointments…..
- Feel informed…..
- Photos are good to support self examination.
- Consultant profile useful, advised re SCAN website.

The participants highlighted that their needs were met when they see the right health care professional at the right time.

- Reassuring- seeing the right person

Overall, participants were happy with their care. However, being mindful of effective communication and care coordination was highlighted.

- Maintain eye contact….
- Don’t discharge to a black hole….. Give advice and training.
- No letter received regarding my appointment- given a recorded message.
- The wait from diagnostic biopsy to wide local excision was too long, causes additional stress.
- Wait for results of SLNB too long.
- Contacted skin cancer link nurse between appointments/procedures.
- There was no offer of support when feeling depressed post treatment.
- It would be useful to have a contact for support ‘out of hours’.
- Need more aftercare specific for amputation – mobilisation, physio, appliances, stairs in houses, ward to car park etc.

There is a need to improve the quality of care transitions and communications across care settings. Establish shared integration of care settings to improve quality of care.

Outcome 4: To understand what impact responsibilities outside of health have on a patient and their family when living with cancer

Many participants highlighted the life challenges that a diagnosis of cancer places on them.
Financial support is not routinely discussed with patients nor healthy lifestyle choices, travel to different hospitals. This can be very difficult with a diagnosis of melanoma as it heightened awareness of life that a diagnosis of cancer brings negative consequences.

- No longer go to warm countries for holidays.
- I will not go on holiday.
- I have become paranoid about sun protection of my children.
- Information on holidays and travel insurance would be welcome.

The impact on work life balance and the consequences of not working:

- I was off for six months....
- I only took a few days off........
- It was okay for me.
- I still work.
- He went back to work after one week – but I like my work.
- I couldn’t work for ages - stitches all split.
- I was off 6 months – chance of infection. Moved leg - it pulled.
- I’m an office worker – left work for one day only initially.
- Had wide local excision – took a few days off - no financial impact .
- Emotional impact – couldn’t do anything with my family, hated being in house.
- I missed a shift for my appointment, financial impact.
- It impacted on work and home, time helped.
- Family life difficult, men don’t cope well, impacts later on.

Direct discussions were had regarding specific aspects of this TCAT project

- Self examination:

- We weren’t given photos – consultant has them on file.
- I’ve got them – we check them regularly. I took photo on camera to begin with.
- If we had photos we could compare differences.
- You can’t look at your back .
- Seeing consultant puts mind at rest – check your body, wife is not a professional.
- It’s good having check-ups.
- Nurse is a good support – if unsure goes for consultant.
- Get written instructions - checklist, - improve service.
- You have to live life – check yourself but it should be a professional to do it – it helps you cope.

Outcome 5: To understand the importance of psychological and social support in helping patients and their families cope with living with cancer

- More support at earliest time is beneficial (everyone agrees).
- That would have helped me – depressed, shocked.
- Maggies was never mentioned. Is there one in this area? We would have used it.
- I’d prefer face to face. Any support is good – highlight resources available.

- Grandson always telling me– put your hat on, cream on, cover up!
• Was sunbathing in Cyprus - it was over 40º, applied loads of sun cream.
• Got partner involved - had to rely on wife storing info and listening.
• The scarring is a problem, I cover up and don’t want people to see.
• I have a new perception of skin cancer – heightened awareness, increased anxiety regarding new lesions.

The ambiguity of the concept of 'needs' and enormity of the task imposed upon practitioners has made the transition from service-led to needs-led much harder, this vagueness is more apparent when a specific need fails to fall neatly into a category.

The failure to address the very real psychosocial health needs of patients and their family is a failure to improve the patients' quality of life. There are reasons to be optimistic. In dermatology substantial support is available but we need to do a better job recognizing a patient's needs and connecting them to the right services – each and every time, for each and every patient.

One of the issues for development following on from the focus group is the development of our psychosocial care.

In doing this we will address the emotional challenges that can accompany a serious illness as well as the life challenges that can prevent good quality of life and patients' ability to care for themselves.

• There needs to be something for children, to help them understand- explain it to them.
• More support early on in the disease is beneficial- that would have helped- I was depressed, shocked….
• Scarring results in body image issues.
• No offer of support when feeling depressed post treatment.
• Family life difficult- men don’t cope well, impacts later on….
• Maggie’s centre is not highlighted for skin cancer patients, patients think ‘their’ cancer is not suitable i.e., only for terminal patients.
• Financial support not highlighted, probably needs highlighting.
• Assume Maggie’s is for people with terminal cancer, therefore not used this service.
• Give sun protection education for friends and families.
• Give advice on sunbathing.

In spite of the availability of these services, the focus group highlighted that ‘health care clinicians’ could better address psychosocial problems and or link patients to available appropriate services.

**Direct discussions were had regarding specific aspects of this TCAT project**

- **Self management event:**

• I would attend.
• Good idea.
• Should be soon after diagnosis.
• Brain is not in gear – shouldn’t be too soon. You are a bit paranoid.
• Would prefer before discharge.
• 1 year down the line -you forget things – better time to reiterate information.
• Visual examples of lesions – how, when to check, get training.
• Can wife and families attend.
• Are there other signs apart from sun awareness, self examination we should know about?
• Live healthily.
• I moan too much about cream, sun etc.
• It would be good to know what you’re doing.
• It should be given at discharge from consultant (appointment for self management group).
• ‘Buddy’ scheme would be good.
• Useful to have information re holidays/travel insurance.
• Opportunity for peer support.
• Opportunity to ask questions.
• Make people aware of what is out there.
• Exercise can increase energy and positivity.
• Would like advice re sun protection for patient and family.
• No advice for fitness and wellbeing – my wife gave me this!

Additional comments:

• Changing rooms would speed up process of clinic/examination.
• Remind patients to wear clothes that are easier to remove.

The importance of understanding the need for physical, psychological, social, spiritual and financial support for people with cancer and their carers is recognised by the dermatology team. Cancer care is a collaborative endeavour and the health care system should explicitly recognize these needs and find ways to meet them.

How we will use the information gathered at the focus group to inform the care of melanoma patients in Fife?

1) We will remind clinicians to think about how best to deliver results of melanoma diagnosis to a patient;
   a) ask patient preference between phone call/face to face.
   b) encourage patient to bring someone.

2) Clinicians and pathologists work together in Fife to ensure pathology results for melanoma diagnosis are in the majority delivered within 4 weeks. This is audited annually so as we can remain aware of delays in this process and act upon them if required.

3) Discussions have been had at the Fife regional skin cancer support group meeting to find ways of how results of sentinel lymph node biopsy tests can be delivered more quickly. The tests are performed in Tayside which is why there is often a delay. Through a process of enhanced communication we hope to tighten up these timescales. A government initiative, melanoma quality performance indicators, commenced in July 2014

All Health boards in Scotland have to submit data detailing the time from diagnosis to wide local excision. The target is for all wide local excisions to be performed within 84 days. This government target will also encourage all regions of Scotland to ensure the wide local excision +/- sentinel lymph node biopsy are performed in a timely manner.
4) As part of the TCAT project we will continue to offer a 7-10 day appointment (post discussion of diagnosis) with the dermatology skin cancer link nurse. This is made when a patient receives their diagnosis. This allows time for the information to ‘sink in’ and for questions to arise.

5) It is evident from feedback that the skin cancer link nurse system works well, patients find it very helpful to have a familiar contact.

6) As part of the TCAT project we will remind patients of how to access the service, between appointments or after discharge, should there be concerns about a new lesion or recurrence. This information will be included in a patient information leaflet, discussed verbally when attending skin cancer link nurse clinic and detailed on clinic letters (see below).

7) As part of the TCAT project we will remind GPs how to access the service, between appointments or after discharge, should there be concerns about a new lesion or recurrence. This reminder will take the form of a few lines at the bottom of every melanoma patient letter, this will detail ‘alert signs’ to look out for and ‘instruction as to how to refer back to dermatology’.

8) As part of the TCAT project all patients will be offered the option of receiving copies of their clinic letters.

9) It is evident that not all patients want to receive a copy of their clinic letter. Patients will be given the opportunity to ‘opt in’ to receiving a copy, this should ensure that letters are only sent out if a patient specifically requests them.

10) The majority welcomed the idea of alternating clinic visits between the dermatology consultant and the skin cancer link nurse. The skin cancer link nurse visits will be longer allowing for time to complete a ‘holistic needs assessment’. At all visits a whole body skin examination will continue to be performed. The skin cancer link nurse clinic will only run when the consultant is also present. This will allow for all decisions to be discussed with the consultant prior to action being taken.

11) At present we do not know when is the optimal time in the melanoma patient pathway to perform the holistic needs assessment. It may vary between patients. As part of the TCAT project we will perform this assessment at all stages of the patient journey. This will provide us with the information we need to decide the optimum time for performing this assessment.

12) We plan to offer all melanoma patients the opportunity to attend a self management group. Feedback from the focus group would suggest that we include the following when thinking about a programme.

   a) Information regarding work/finances.
   b) Consideration of the impact on families and children.
   c) Skin examination.
   d) Sun protection.
   e) Introduction to Maggie's centre.
   f) Psychosocial support from other melanoma sufferers/families.
   g) Opportunity for a ‘buddy scheme’.
   h) Invite family member/carer.
   i) Consider holding meeting outside normal working hours.

All information gathered as part of the focus group and during the journey of the TCAT project will be disseminated regionally and Nationally. This will allow us to inform colleagues so as they can alter their
management of the melanoma patient journey to include aspects of the project which have been found to be helpful.

We would like to thank all patients and carers who took part in the melanoma patient focus group meeting.

Dr Megan Mowbray  
NHS Fife Lead Skin Cancer Clinician  
SCAN skin group Chair

Murdina MacDonald  
MacMillan Lead Cancer Nurse
Background
Malignant melanoma of the skin is currently the 6th most common cancer in Scotland. Melanoma has increased in incidence in Scotland over 50% in the last 10 years (1995 data). Approximately 60 melanomas are diagnosed in Fife each year. Referrals from primary care to dermatology continue to increase each year. Of the 3,000 referrals to the NHS Fife dermatology service each year 49% of them are skin cancers (15% benign, 15% skin cancer). The annual increase in dermatology referrals impacts on the capacity of the skin tumour clinic to meet the holistic needs of the melanoma skin cancer patient.

The South East Scotland Skin cancer network (SCAN) has a regionalskin cancer support nurse based in Lothian. In 2000 we developed two local skin cancer nurse led (SCNL) at each of the two hospital sites in NHS Fife, Victoria Hospital Kirkcaldy and Queen Margaret Hospital Dunfermline. The SCNL works as a dermatology nurse but has additional training in skin cancer. All Fife dermatology consultants work on split days. A skin nurse is always available at each hospital site. A skin nurse will meet a patient and their carer at the time of diagnosis and 3-10 days following diagnosis. She will provide support to the patient throughout their journey and acts as a link to other specialties.

Following active treatment, melanoma patients attend consultant led follow up clinics in the department of dermatology (table 1).

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Results

Outcome 1: To understand what happens when a patient receives a diagnosis
- Shocked-flushed-can't remember giving home
- S突发的，打算回家，但已经出院
- I thought something had happened to my legs...
- Don't take this, I thought I was having a brain haemorrhage...
- Remember asking, what is melanoma?
- Doctor phoned and said 'you've got cancer'.
- Why us?
- I didn't return home until I spoke with the skin cancer link nurse.
- Quick appointments cause alarm.
- Expect someone with you for extra support.
- Need time to come to terms with diagnosis.
- MEETING (waiting list interactive clinic) – extended timescale from referral to appointment and results cause distress.
- Would have been more beneficial to receive written information at consultation.
- Internet information – covered a lot of research.
- Doctors how patient would like to be informed of their results, asked before time of investigation – by phone, in clinic.
- Attended clinic alone, felt isolated.
- Advised that patients are welcome to bring someone with them.
- Driving after receiving results could be dangerous.

All patients recognised they need time to discuss their diagnosis, but there is not a one ‘fit for all’. It was suggested that patients should be offered a choice of how to get the results of investigations which lead to a diagnosis – either at home (phone) or at hospital. Equally, the time for performing a melanoma may vary depending on the patient.

Outcome 2: To understand the level of support required
Direct discussions were held about accessing the service between appointments or after discharge, this is what patients and their families told us:
- I would phone SCNL she gave us a card – we look for any changes in moles.
- Go to someone you know and whose you – SCNL.
- GP may not have seen enough patients – should be trained better.
- GP would recognise it straight away.
- It is good to know what to do in between clinic appointments.
- I am concerned my last appointment is coming up. Makes me wary.
- Link nurse is a nice touch (inclusive).

Outcome 4: To understand what impact responsibilities outside of health have on a patient and their family when living with cancer
- A lot of time goes on family (92% agreed).
- I will not go on holiday.
- I have become paranoid about sun protection of my children.
- Information on holidays and travel insurance would be welcome.

The impact on work life balance and the consequences of not working:
- I was off for six months...
- I only took a few days off....
- It was okay for me.
- I still work.
- I didn't work after one week – but I like my work.
- I could work part time – didn't work.
- I worked for two weeks – change of job. Moved in; - pulled out.
- I am an office worker – left work for one day only initially.
- Had to take a couple of days off – no financial impact.
- Emotional impact – thought it was going to be different to anything with my family, took being in house.
- I missed a shift for my appointment, financial impact.
- It impacted on work and home, time help.

Discussions were had regarding self examination
- If we had photos we could compare differences.
- You can't look at your back.
- Seeing consultant puts mind at rest – check up your body; own is not a professional.
- It's good having check-ups.
- Nurse is a good support – if unsure goes for consultation.
- Get written instructions – checklist.
- You have to live life – check yourself but it should be a professional to do it – keeps you cope.

Outcome 5: To understand the impact of psychological and social support in helping patients and their families cope with living with cancer
- More support at earliest time would be beneficial (everyone agreed).
- Magisters was never mentioned. Is there one in this area? We would have
Macmillan Transforming Care After Treatment (TCAT) Programme

Macmillan recognizes the increasing incidence of all cancers. The TCAT programme aims to transform care after treatment to optimize care, encourage self-management, and ensure medical resources are directed most appropriately.

NHS Fife Dermatology TCAT project

Over a 5-year period the SCULN has become invaluable to patients and clinicians. The TCAT project aims to change the role of the SCULN and other aspects of melanoma patient care in line with the aims of TCAT.

1. Develop role of SCULN nurse led melanoma follow-up clinic alternating with outpatient follow-up. Clinic to include rapid access appointment, Holistic needs assessment (HNA) to be performed at SCULN clinic.
2. Utilize the support resources currently available across health, social care and the 3rd sector.
3. Develop the role of a plastic surgery SCULN.
4. A method of rapid access back into secondary care following discharge will be developed.
5. Develop an electronic end of treatment summary.
6. Patients to opt in or opt out as to whether to have a copy of their clinic letters.

A patient focus group was held to determine how melanoma patients in Fife view their current care. Patient opinion was sought regarding the Fife dermatology TCAT project.

Patient focus group

Discussion was designed to gather information in relation to the following:

- To understand what happens when a patient receives a diagnosis;
- To understand the level of support required by patients;
- To understand how patients and carers perceive NHS Fife’s effectiveness in treating their needs;
- To understand what impact responsibilities outside of health have on a patient and their family when living with cancer;
- To understand the importance of psychological and social support in helping patients and their families cope with living with cancer.

20 participants took part in the focus group, 15 women, 5 men, 16 patients, 4 carers. The participants were divided into 2 groups, each with a facilitator and scribe. Each facilitator followed a format developed to elicit insight into the outcomes listed above.

Outcome 3: To understand how patients and carers perceive NHS Fife’s effectiveness in meeting their needs

- At the end of contact with plastic surgery all patients felt they had received enough information.
- I am now more aware of examining my partner/relatives.
- The felt it consultants don’t have time to discuss social issues.

Comments regarding opt in for copy of clinic letter for patient

- Reflected anxiety; good idea.
- We would have panicked if we hadn’t seen it written in a letter.
- Any information is good, at least you can discuss contents of letter.
- This would be helpful.
- General feedback that it would be helpful, e.g. husband was always at work at time of clinic appointment.

Direct discussions were had regarding Nurse led clinics:

- Wouldn’t bother me attending – good service.
- What authority would they have? To remove lesion etc.
- Don’t always meet expectations – I saw same nurse.
- Appointment with link nurse to discuss general well being would be good.
- Would welcome alternative out patient appointments with consultant skin cancer link nurse.
- I would still want the consultant to examine my skin.

The patients highlighted that their needs were met when they saw the right health care professional on the right time.

- Reassuring; seeing the right person.
- Overall, participants were happy with their care. However, being mindful of effective communication and care coordination was highlighted.

Conclusions from patient focus group

1) Clinicians to think about how best to deliver results of melanoma diagnosis to a patient:
   a) Ask patient preference between phone call/speech to face.
   b) Encourage patient to bring someone.

2) Clinicians and pathologists to ensure pathology results for melanoma and SLNB are delivered an efficiently as possible. This complements the melanoma quality performance indicators which require a local histological result to be performed within 24 hours of diagnosis.

3) Continue to provide a 3-4 day appointment (post discussion of diagnosis) with the dermatology skin cancer link nurse. Feedback indicates that the SCULN system works well.

4) Remind patients of how to assess the scar, between appointments or after discharge, should there be concerns about a new lesion or recurrence.

5) Patients will be offered the option of receiving copies of their clinic letters.

6) commence SCULN review clinic, alternating with consultant follow-up, allowing time for ‘clinical needs assessment’.

7) Melanoma workshop programme to include:
   a) Information regarding work finances.
   b) Consideration of the impact on families and children.
   c) Skin examination and protection.
   d) Introduction to Maggie’s centre.
   e) Psychological support from other melanoma sufferers/families.
Appendix 6 – Holistic needs assessment

National Cancer Survivorship Initiative – Concerns checklist

Identifying your concerns

Discussed by: _____________________________
Date: ____________________________________
Designation: _____________________________
Contact details: ___________________________

Patient's name or label

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.

<table>
<thead>
<tr>
<th>Physical concerns</th>
<th>Pracitical concerns</th>
<th>Spiritual or religious concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Breathing difficulties</td>
<td>□ Caring responsibilities</td>
<td>□ Loss of faith or other spiritual concern</td>
</tr>
<tr>
<td>□ Passing urine</td>
<td>□ Work and education</td>
<td>□ Loss of meaning or purpose of life</td>
</tr>
<tr>
<td>□ Constipation</td>
<td>□ Money or housing</td>
<td>□ Not being at peace with</td>
</tr>
<tr>
<td>□ Diarrhoea</td>
<td>□ Insurance and travel</td>
<td>or feeling regret about the past</td>
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<tr>
<td>□ Eating or appetite</td>
<td>□ Transport or parking</td>
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<tr>
<td>□ Indigestion</td>
<td>□ Contact/communication with NHS staff</td>
<td></td>
</tr>
<tr>
<td>□ Sore or dry mouth</td>
<td>□ Housework or shopping</td>
<td></td>
</tr>
<tr>
<td>□ Nausea or vomiting</td>
<td>□ Washing and dressing</td>
<td></td>
</tr>
<tr>
<td>□ Sleep problems/nightmares</td>
<td>□ Preparing meals/drinks</td>
<td></td>
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<tr>
<td>□ Tired/exhausted or fatigued</td>
<td></td>
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<tr>
<td>□ Swollen tummy or limb</td>
<td></td>
<td></td>
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<tr>
<td>□ High temperature or fever</td>
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<td>□ Getting around (walking)</td>
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<td>□ Tingling in hands/feet</td>
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<td>□ Pain</td>
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<td>□ Hot flushes/sweating</td>
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<td>□ Dry, itchy or sore skin</td>
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<td>□ Wound care after surgery</td>
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<tr>
<td>□ Memory or concentration</td>
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<tr>
<td>□ Tests/sight/hearing</td>
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<td>□ Speech problems</td>
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<tr>
<td>□ My appearance</td>
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<tr>
<td>□ Sexuality</td>
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<table>
<thead>
<tr>
<th>Family/relationship concerns</th>
<th>Emotional concerns</th>
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<tbody>
<tr>
<td>□ Partner</td>
<td>□ Difficulty making plans</td>
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<tr>
<td>□ Children</td>
<td>□ Loss of interest/activities</td>
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<td>□ Other relatives/friends</td>
<td>□ Unable to express feelings</td>
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<td></td>
<td>□ Anger or frustration</td>
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<td>□ Guilt</td>
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<td>□ Hopelessness</td>
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<td>□ Loneliness or isolation</td>
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<td>□ Sadness or depression</td>
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<td></td>
<td>□ Worry, fear or anxiety</td>
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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.

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<td>1</td>
<td>10</td>
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</table>

Lowest               | Highest

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Appendix 7 – Sample page of directory of services

1 Physical Concerns

If a Patient highlights any concerns with health related problems, e.g. shortness of breath, bleeding etc, this should be reported to the Consultant leading the Tumour Clinic or the Patients own Consultant. The Consultant will then decide after examining the Patient if they are to be referred to another speciality for a second opinion or if the Gp can deal with the presenting problem. However if the problem can be addressed by the Clinic Nurse the following Services are available that will take referral from Nurse Led Clinics:

<table>
<thead>
<tr>
<th>Concern</th>
<th>Service</th>
<th>Contact</th>
<th>Service provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathing difficulties</td>
<td>NHS</td>
<td>Consultant, GP, CNS or Palliative Care Nurse</td>
<td>Offering support and advice on diet and nutrition. <strong>MUST score must be 2 or greater – see appendix.</strong></td>
</tr>
<tr>
<td>Eating or appetite</td>
<td>Community Dietetics &amp; Nutrition</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Department</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating or appetite, sore or dry</td>
<td>Macmillan</td>
<td></td>
<td>Booklet “Eating Problems and Cancer” Information on Macmillan website and online chat forum. Macmillan Recipe Book.</td>
</tr>
<tr>
<td>mouth.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tired/Exhausted or Fatigued</td>
<td>Macmillan</td>
<td></td>
<td>Coping with Fatigue Booklet.</td>
</tr>
<tr>
<td>Swollen limb</td>
<td>Lymphoedema Service Hospice, VHK &amp; QMH</td>
<td>Lorraine Smith, Hospice, VHK, - ext 20172</td>
<td>Physiotherapy service for patients diagnosed with cancer who have had swollen limbs after SLNB</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Alison Green, Hospice, QMH, - ext 26641</td>
<td></td>
</tr>
<tr>
<td>Getting around (walking)</td>
<td>District Nurses</td>
<td>GP Surgery</td>
<td>Walking aid assessment if required.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Footcare in Fife (Kirkcaldy/Levenmouth)</td>
<td>Low cost service run by local charity to provide assistance to manage personal footcare.</td>
</tr>
<tr>
<td>Dry, itchy or sore skin</td>
<td>Macmillan</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wound care after surgery</td>
<td>Plastic Surgery Specialist Nurses</td>
<td>Lynn Coyne,</td>
<td>For advice and advanced dressings after wide local.</td>
</tr>
</tbody>
</table>

Page 84
| (Melanoma)                      | Deborah McCallum  
Ext 25757 | excision or sentinel lymph node biopsy. |
|--------------------------------|------------------|--------------------------------------|
| Dermatology Department         | Charge Nurse Gail Mitchell VHK  
Charge Nurse Una Donaldson QMH | For advice after biopsy and wide local excision |
| Wound care after surgery (Other Cancers) | Consultant/GP/Nurses | For advice and management of dressings |
| My appearance                  | Changing faces    | Dierdre O’Flynn – 0131 659 2942  
Or dermatology nurse can refer | Cosmetic camouflage of scarring |
| Boots No7                      | Kirkcaldy Retail Park- Cheryl Hudson and Jennifer Irvine (01592-644139)  
Kirkcaldy High Street- Lorraine Elder (01592 -263781)  
Dunfermline - Nan Anderson (01383- 737474) | A free drop-in service to enable patients to manage changes to their skin, hair and nails.  
There is a booklet “Feel more like you” which has lots of expert tips about coping with changes. |
| Sexuality (erectile dysfunction) | Urology Specialist Nurse | CNS Ruth Cameron ext 22626 or email, give patients name, chi, GP, contact no, brief history of complaint and condition. | For referral of concerns regarding erectile dysfunction. |
| Sexuality (Relationship problems) | Macmillan | Monday to Friday 9am – 8pm 0800 808 0000 | Range of information and booklets available from website. How cancer can affect your sexuality. |
Appendix 8 – Standard melanoma letter

Victoria Hospital
Hayfield Road
Kirkcaldy
Fife
KY2 5AH

Tel: 01592 643355 28634
http://www.nhsfife.scot.nhs.uk

CHI: XXXXXXXXXX
Hospital ID: XXXXXXXX

Letter ID: XXXXXXX

Dear XX

Clinic Date: XX/XX/XXXX
Date: XX/XX/XXXX

Patient name & address
Date of Birth: XX/XX/XXXX

Diagnosis
Melanoma type, site, date diagnosis
Breslow
Mitotic rate
Wide local excision +/- Sentinel lymph node biopsy – date + outcome
AJCC stage

Investigations

Management
Information given – SCAN flyer, melanoma, SLNB leaflet
Sunsense lotion SPF 50 recommended
Whole Body Photographs performed/not required – date

Melanoma workshop
Attended (date) / declined invite / to be invited

Treatment aim
Curative/Palliative

Patient copy clinic
letter opt in/opt out

Review

4/12 Dr XX

Free text as dictated by Clinician or dSCLN

1st paragraph, general + examination, 2nd paragraph, HNA comments

Yours sincerely
Dr XX / SCLN

GP READ code – malignant melanoma B32
Alert symptoms requiring re-referral – change in skin at site of melanoma. Change in colour, shape or size of an existing mole. New growing nodule with or without pigment. Lymphadenopathy or organomegaly.
Referral to dermatology
If patient currently under dermatology follow up – patient to phone skin cancer link nurse to make an urgent review appointment. If patient has been discharged – GP to refer urgently to dermatology
South East Scotland Cancer Network (SCAN) patient information http://www.scan.scot.nhs.uk/CancerInformation/skin/Pages/default.aspx
The updated Scottish dermatology management and referral pathways are now available at www.dermatology.nhs.scot and as an app from the itunes and android stores.
TCAT Melanoma Workshop Feedback

During 2016, 4 workshops were completed and 32 patient feedback questionnaires were returned.

How would you describe the workshop to a friend?

The word cloud below shows the words used by patients to describe the workshop, the bigger a word appears on the cloud, the more frequently it was mentioned by patients. This illustrates that patients used “informative” most frequently.

In what year were you diagnosed?

Year of diagnosis was missing for 1 patient. Majority of the patients were diagnosed in 2015 (N=15, 48%).

How useful did you find the workshop?

Majority of patients found the workshop “Very useful” (N=22, 69%).
How well do you feel it matched what you were hoping for?

Majority of patients felt the workshop matched what they were hoping for “Very well” (N=19, 60%). One patient commented that it “covered more than I thought” and another patient said they were “not sure what to expect”.

Was it relevant/helpful to your current situation?

Data was missing for 1 patient. The majority of patients felt that the workshop was “Quite” relevant to their current situation (49%). There was no correlation with year of diagnosis and how helpful the workshop was to patient’s current situation. One person, diagnosed in 2014 commented that it “would have been better earlier on”.

How happy were you with the content of the workshop (Partnering your medical team) 

Majority of patients (n=21, 66%) were “Very happy” with partnering your medical team. One patient was “unhappy with partnering medical team as “my team wasn’t there”.

How happy were you with the content of the workshop (Emotional wellbeing):

Majority of patients (N=24, 75%) were “Very happy” with emotional wellbeing
How happy were you with the content of the workshop (Advice about benefits)

1 patient did not respond to this question. Of the remaining patients, the majority (N=18, 58%) said they were “Very happy” with advice about benefits.

How happy were you with the content of the workshop (Community Connections - How Fife Council can support you)

1 patient did not respond to this question. Of the remaining patients, the majority (N=13, 42%) said they were “Very happy” with advice about how Fife Council can support you.

How happy were you with the content of the workshop (Where now):

3 patients did not answer this question. For the remaining patients, majority (N=14, 48%) were “Very happy” with Where now.

What did you think of the facilities?

Majority (N=21, 66%) of the patients though the facilities were “Excellent”. Comments from patients included “friendly atmosphere Great to see the facility seats a bit hard room quite hot not big enough”
Was the time of day suitable?

2 patients did not answer this question. Of the remaining patients, 90% (n=27) of attendees said the time of day was suitable. Three patients suggested non-working hours would be better and one patient suggested morning would be better.

What about the length of the workshop, chances for breaks etc.

Majority (56%) of the patients rated the length of the workshops as “Excellent”. One patient commented that the workshops went at a “pleasant speed”.

Was there a chance to meet and talk with others in your situation? If yes, what did you think of the chance to talk?

All patients had the chance to meet and talk. One patient did not rate the experience. The remaining patients majority (52%) rated the experience as “Good”.

The comments from patients included:

“Think it would have been beneficial to give the group more opportunity to discuss their experiences more, Was left open and informal, To quote Diabetes UK, we are not alone, Nice to hear others experiences”

How confident are you to manage your condition by yourself?

Majority (N=15, 47%) of patients said they are “More Confident” to manage their conditions themselves.
What sections of the workshop did you most enjoy?

Patients highlighted enjoying the Partnering your medical team (12) and Emotional wellbeing (11). Patients enjoyed chatting and sharing experiences with other patients (5) and 5 patients commented that they enjoyed all of it- “Each had something to offer, so one not more enjoyable that the other”.

Specific comments are also shown below

- Patterning your medical team- “I could really relate to this talk”
- Emotional wellbeing- “I can relate to pretty much everything I heard. I have lots of issues I feel need to be addressed”
- “realising that support is provided by different agencies”

In what ways do you think we could improve the workshop?

| 6 patients commented that nothing could be improved | 4 patients discussed rolling out the workshop to other areas- “take it on the road” |
| Workshop available in most council area | 2 patients commented that they would have liked more interaction with other patients |
| More interactive session- sharing experiences and concerns | more opportunity to discuss with fellow patients |

Any other comments?

In this section patients said they really enjoyed the workshop, and thank you!

One patient said “good to have time to meet others and be able to find out about support available”.

One patient commented that they were disappointed their link nurse wasn't there.
Melanoma Skin Examination

Once a month examine your skin from head to toe. Look for any mole, spot or bump that seems to stand out because of being:

● Dark ● Different ● Changing

When examining a mole of any size, look for the ABCDE’s of melanoma. Most melanomas have at least one of these features.

Asymmetry
Does any one half look different from the other half in colour/shape?

Border
Does a mole have an irregular, jagged or blurred border?

Colour
Does a mole have different colours or different shades of one colour?

Dark
Does a mole appear dark, or does any dark area within a mole appear dark?

Evolving
Has a mole, spot, or bump evolved, or changed, in a way unlike others on your body?

A general rule is that any mole that looks different from all of your other moles should be evaluated.

‘ugly duckling sign’
Sometimes the most dangerous melanomas can be recognised because they grow quickly and look different from any other bump that you have. These are called ‘nodular melanomas’ they can be any colour, including black, blue, red, pink or flesh coloured.
Appendix 11

A list of all stakeholders involved with Melanoma TCAT project

<table>
<thead>
<tr>
<th>STAKEHOLDER</th>
<th>TITLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Megan Mowbray</td>
<td>Consultant Dermatologist &amp; Project Lead</td>
</tr>
<tr>
<td>Dr Susannah Fraser</td>
<td>Consultant Dermatologist</td>
</tr>
<tr>
<td>Murdina McDonald</td>
<td>MacMillan Lead Cancer Nurse &amp; Assistant Project Lead</td>
</tr>
<tr>
<td>Dr Neil Pryde</td>
<td>Lead GP NHS Fife</td>
</tr>
<tr>
<td>Sandra Bagnall</td>
<td>SCAN MacMillan Project Manager</td>
</tr>
<tr>
<td>Gordon McLean</td>
<td>TCAT Project Manager MacMillan</td>
</tr>
<tr>
<td>Fiona Sneddon</td>
<td>Partnership Quality Lead, MacMillan</td>
</tr>
<tr>
<td>Elizabeth Preston</td>
<td>SCAN Clinical Lead - Transforming Care after Treatment</td>
</tr>
<tr>
<td>Elaine Hanacock</td>
<td>Skin Cancer Link Nurse</td>
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<tr>
<td>Carol Scorgie</td>
<td>Skin Cancer Link Nurse</td>
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<tr>
<td>Stuart Waterston</td>
<td>Plastic Surgeon</td>
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<tr>
<td>Deborah McCallum</td>
<td>Plastics Skin Cancer Link Nurse</td>
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<tr>
<td>Caroline Turnbull</td>
<td>Plastics Skin Cancer Link Nurse</td>
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<tr>
<td>Alison Harrow</td>
<td>Manager, Maggie’s Centre Victoria Hospital</td>
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<tr>
<td>Alison Watt</td>
<td>Project Manager, Integrated Community Cancer Care – Phase 2 TCAT Project</td>
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<tr>
<td>Jackie Stevenson</td>
<td>Cancer Audit Facilitator &amp; Local audit/evaluation support</td>
</tr>
<tr>
<td>Mary Kerr</td>
<td>Dermatology Secretary &amp; TCAT secretarial support</td>
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<tr>
<td>Lucy Johnston</td>
<td>Lecturer Edinburgh Napier University</td>
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<tr>
<td>Ian Stone</td>
<td>Melanoma TCAT Project Patient Representative</td>
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