MELANOMA SHARED CARE

A tripartite approach for survival, the patient, their GP and their specialist

Version 2 – June 2014
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Foreword

This is the final report prepared for the Department of Health, Survivorship Steering Committee to summarise and evaluate the project titled “Melanoma Shared Care: A tripartite approach for survival, the patient, their GP and their Specialist”. The project and its evaluation were conducted in accordance with the project plan developed by the Melanoma Survivorship Project Team (MSPT). This report reviews aims, activities and outcomes of the project. It identifies key findings and makes recommendations on how the interventions of this pilot project can be embedded in current practice.

Acknowledgements

The pilot project was jointly funded by the Victorian Government, Department of Health and the Gippsland Regional Integrated Cancer Service (GRICS), with in kind funding provided by the Southern Melbourne Integrated Cancer Service (SMICS).

Key Message

Melanoma survivors comprise a large group of long term survivors, as well a a smaller group of short terms survivors including young adults with special needs.

The economic cost of management of both groups needs consideration and patients can be helped to cope with their diagnosis by placing a focus on education at the conclusion of acute care.

This pilot demonstrated that it is at this clinical point that patients can be fully educated regarding their individual prognosis and assisted to understand the need for a plan of surveillance to detect recurrent and new disease. Follow-up surveillance plans should be based upon risk stratified protocols to avoid under and over servicing.

The conclusion of acute care was also used to commence a trial of continuous supportive care and though the methodology of achievement of this goal needs refinement, it is possible. During this trial patients had direct involvement in the planning and execution of their surveillance and discharge. Medical staff were obligated to ensure they had discussed this to provide patients with a sense that care would continue in a structured way after discharge.
Executive summary

Victoria’s Cancer Action Plan 2008-2011 identified the need to improve the experience of cancer patients, their families and carers at every point of the cancer pathway by:

- offering treatment and care as close to home as possible
- ensuring the right care in the right place at the right time
- providing for and supporting a patients’ choice to care, treatment and information
- strengthening links between health services, particularly metropolitan and rural services

Patient Management Frameworks (PMFs) were developed in 2006 by the then Department of Health (previously known as the Department of Human Services) for each of ten tumour streams. The PMFs describe optimal care and management from diagnosis to end-of-life care and aim to reduce unwanted variation in care. The melanoma PMF states that follow up should be multidisciplinary with general practitioners (GPs) having a key role in the co-ordination of follow-up care, though the individual GP is likely to have small numbers of patients requiring follow-up care for melanoma.

Shared Care

It has already been shown that general practitioner (GP) led follow up can provide equivalent medical outcomes, more holistic care, improved patient satisfaction and more guideline compliance than specialist led follow-up. This must be complemented by expert guidance regarding guidelines and ready access to specialist clinical advice and further acute care in a seamless way.

Influence of melanoma incidence and long term survivorship

- In 2012 six new patients received a melanoma diagnosis in Victoria every day
- In 2012 the five year survival rate was above 90%
- Melanoma incidence in Victoria increased from 15 to 28/ 100,000 persons between 1982 and 2004
- Melanoma is the fourth most common cancer overall in both men and women
- Melanoma is the most common cancer in the young (aged 15 to 29)
- The strongest risk factor for melanoma is a past history of melanoma and therefore survivors require lifelong surveillance for recurrent and/or new melanoma

These factors have resulted in increased demand on acute health care providers and a need to provide efficient, effective and economically rational care for survivors.

Objectives

The pilot project sought to meet the objectives of the Victorian Cancer Action Plan by:

- enhancing links and sharing of care between specialist and local practitioners and between community and hospital based services (shared care)
- having an agreed plan for care to which all parties adhere
- enhancing compliance with the agreed plan by all parties
- reduce problems related to movement between service providers such as failure to have reports of investigations immediately available to all providers as they are seen
- educating doctors about prognosis, evidence based surveillance and survivor needs
- educating patients to empower them to participate in the decisions made about them
- educating patients regarding risk factor modification, early detection of new and recurrent disease and general healthy lifestyle choices
- testing a method of alerting patients of their supportive care needs on a continuous basis
Project design
This project was designed as a non-experimental exploratory pilot of interventions that built on and refined existing interventions to test whether the refined interventions could be practically included in standard practice.

This included education regarding melanoma for patients and doctors, the creation of awareness that survivors have needs beyond acute care, the creation of documents for that process, reinforcing a protocol (and where possible evidence based) approach to survivorship and following up individuals to see if the interventions had the intended impact.

Project Stages
The stages of the project were:

- a literature review to determine what evidence base existed about the planned interventions
- a questionnaire for patients previously diagnosed with melanoma to understand what their needs may be
- document and process design stage
- ethics approval
- production of project documents and selection of education materials
- education of participating doctors at Victorian Melanoma Service
- recruitment of patients and engagement with their doctors to increase compliance with the plan
- development of an active learning module for GP education
- surveying participants over a 12 month period following recruitment
- creation of an MS Access database to collect and analyse data
- analysis of the data to determine whether this project has made a difference to the wellbeing of the participants
- reviewing pre pilot patient discharge correspondence for change induced by the pilot

Project cohort
Patients residing throughout Victoria were recruited from those discharged from the Victorian Melanoma Service (VMS) in the setting of a multidisciplinary team (MDT). Although not initially part of the project plan, the project team considered that if time and resources permitted, a second phase would be undertaken involving doctors in the SMICS and GRICS catchment areas to provide a test of the interventions in a community setting, however this did not eventuate.

Evaluation
Quantitative and qualitative data was achieved by use of electronic surveys and retrospective file audit.

Outcomes
Individual participant’s outcomes
The majority of respondents indicated that they were following the recommended risk stratified treatment and surveillance plan with only minimal divergence. The divergence related to frequency in the areas of self-examination and attendance at follow up appointments within the recommended timeframe.

Personal utilisation of the diary was high, with 77.3% (34) utilisation recorded in round one and 82.4% (28) in round two.

Round one data indicated that 56.8% (25) respondents regularly took their diary with them to all of their follow up appointments and 15.9% (7) only sometimes took their diary with them. Round two data indicated 55.6% (15) attended appointments with their diary and 33.3% (9) only taking the diary with them sometimes.
The usefulness of the melanoma diary increased over time. Round 1 responses were rated as very useful 26.8% (11), somewhat useful 41.5% (17), not very useful 24.4% (10), not at all useful 7.3% (3). Round two responses regarding the usefulness of the diary rated as follows, very useful 45.5% (15), somewhat useful 39.4% (13), not very useful 9.1% (3) and not at all useful 6.1% (2). Those who found the diary not very useful during round one data collection 24.4% decreased to 9.1% in the second round of data collection, illustrating an improvement in the perceived usefulness of the diary over time.

Those that found the diary not at all useful remained relatively the same in both rounds of data collection with some comments received indicating that they had understood their prognosis was extremely good and did not wish to invest further time in the diagnosis.

The pilot has led to increased yearning for what may be termed an “active” electronic medical record. One that goes way beyond recording the past and becomes an interactive tool that self-populates with information, education links, plans and protocols according to entered data and ensures what is planned is what happens and enabling all involved parties access to the same set of information.

Acceptability of program participants
The acceptability of the pilot project and associated interventions was evident from the commencement of participant recruitment. Of the 107 people invited to participate only three declined. Forty five participants responded to the first round of evaluation, all (100%) respondents indicated that they wanted to continue using the interventions and continue to participate in the pilot project.

Evidence to support the acceptability of the program in the area of general Practice is inconclusive as the response to surveys was minimal and requires further follow up to provide a true and measurable result. However, the acceptability of the Active Learning Module (ALM) was proven by seven of the eight participants who informed the learning objectives outlined in the module were completely met and that they would recommend the education program to their colleagues.

Effectiveness of program for participants
Similar to other interventions of the pilot, the longer the interventions were in place the greater effectiveness participants assigned to them increased. The final round of data collection demonstrated that 76% of respondents indicating that they valued the shared care arrangements.

The information and resources provided to participants to assist them to be empowered and actively involved in their self-management was highly valued with only a single respondent indicating that they were not valued.

Participants reported that the health care professionals who most commonly referred to the Personal Melanoma Diary (PMD) during follow up consultations with survivors were general practitioners, closely followed by dermatologists and then general practitioners with a specific interest in melanoma.

Cost benefits/limitations for individual participants
Although a formal cost analysis was not conducted, the risk stratified pathways were devised to decrease over investigation, reducing the economic impact on both the individual and the health service system.

Cost benefits/limitations for community and specialist stakeholders
These measures are economically sustainable with potential for cost savings if GP resources are used more effectively. The project interventions can be implemented and disseminated even in the absence of randomised control trial evidence of benefit, if enthusiastic individuals and groups pursue it as “good medicine”.

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Melanoma Shared Care Survivorship Pilot Project Evaluation Report – V2 June 2014
Sustainability of the program beyond the life of the project to broader national melanoma cancer services and other tumour streams

Overall, the pilot has demonstrated that shared care is achievable in melanoma survivorship with simple measures and that patients will engage with post-acute care.

Recommendations

1. The interventions of this pilot should now be tested by expansion into a full formal study. This would require the recruitment of the other multidisciplinary care sites within Victorian hospitals and community practitioners with a particular interest in melanoma management. This would include a full statistically-based evaluation of the interventions and their periodic review and alteration according to patient feedback.

2. The active learning module for melanoma should be reviewed, improved, and offered across all general practitioner education groups in Victoria. This would be to the immediate benefit of melanoma survivors, the expansion of survivorship projects and interest throughout the entire melanoma survivorship community.
Section 1: Background/Context

1.1 Health service for the pilot

The Victorian Melanoma Service (VMS) was established in 1994 at the Alfred Hospital as an outpatient service for patients with biopsy proven melanoma (primary or metastatic). The service maintains an active program of research in melanoma including trials of new treatments. It is a fully multidisciplinary consultative centre for the management of melanoma. Its objective is to provide a comprehensive assessment by all the specialties involved in the treatment of melanoma at a single site to achieve seamless care and a consensus management plan. It includes experts in dermatology, pathology, medical oncology, radiation oncology, general surgery, plastic surgery and psychology and thereby provides a comprehensive service.

The philosophy of the clinic is patient centred. Patients are encouraged and supported to make their own decisions regarding management.

The VMS is situated within the Alfred Hospital, a major tertiary referral teaching hospital. It has a major role in the provision of specialist tertiary services on a state-wide and national basis.

1.2 Catchment population demographics

In 2012, Melanoma was the fifth ranking new cancer in Victoria, with a total of 2,261 new cases diagnosed and a high five year survival rate of 90%.

The VSM reviewed 537 newly diagnosed melanoma patients in 2013, evenly split between genders (268 female, 269 male) as shown in table 1.

<table>
<thead>
<tr>
<th>Year</th>
<th>Month</th>
<th>Female</th>
<th>Male</th>
<th>Total</th>
</tr>
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<tbody>
<tr>
<td>2013</td>
<td>July</td>
<td>28</td>
<td>18</td>
<td>46</td>
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<tr>
<td></td>
<td>August</td>
<td>13</td>
<td>19</td>
<td>32</td>
</tr>
<tr>
<td></td>
<td>September</td>
<td>20</td>
<td>22</td>
<td>42</td>
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<td></td>
<td>October</td>
<td>30</td>
<td>17</td>
<td>47</td>
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<td></td>
<td>November</td>
<td>25</td>
<td>20</td>
<td>45</td>
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<td></td>
<td>December</td>
<td>16</td>
<td>22</td>
<td>38</td>
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<td></td>
<td>January</td>
<td>18</td>
<td>33</td>
<td>51</td>
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<td></td>
<td>February</td>
<td>23</td>
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<tr>
<td></td>
<td>June</td>
<td>24</td>
<td>21</td>
<td>45</td>
</tr>
<tr>
<td>2013 Total</td>
<td>268</td>
<td>269</td>
<td>537</td>
<td></td>
</tr>
</tbody>
</table>
Of the 537 melanoma patients attending the VMS in 2013, 104 were recruited to the pilot project. The area of which the participants reside was widely spread across Victoria as demonstrated in the catchment area map below.
1.3 Needs Assessment

Melanoma is a common disease in Victoria

In Victoria, melanoma is the fourth most common cancer overall. 2,261 Victorians were diagnosed with melanoma in 2012 (that is equivalent to six diagnoses every day).

- melanoma incidence in Victoria increased from 15 to 28/100,000 persons between 1982 and 2004
- melanoma is the fourth most common cancer for Victorian women (behind breast, bowel and lung)
- melanoma is the fourth most common cancer in Victorian men (behind prostate, bowel and lung)
- the most commonly diagnosed cancer among adolescents and young adults is melanoma
- melanoma survivors are numerous
- in 2012 90% of those diagnosed with melanoma survived, which is an improvement from 85% in 1985

An escalating incidence means there is an increasing, potentially huge, pool of survivors who will live a long time and need long-term management. This creates a need for consideration of public expenditure.

Melanoma has a high profile in the community

Melanoma is well known in the Australian community, as the nation with the highest incidence of this disease it is often known as “Australia’s Cancer”. Because the induction of melanoma is strongly linked with sun exposure, and the Australian lifestyle includes very high levels of sun exposure, public education campaigns to change this “bad behaviour” are many and intense. Educators frequently project its sinister fatal aspects to capture public attention and change behaviour.

Melanoma is the highest cause of cancer specific death in young adults, meaning many people have direct experience of tragic stories of lives cut short. At the time of diagnosis, survivors are often very fearful and remorseful, and have to face up to public advertising campaigns reminding them of the potential of their diagnosis.

Most patients and many doctors are not aware of the fact that 95% of patients who receive a melanoma diagnosis do not succumb to the disease and will be very long-term survivors. Patients at very low risk of recurrent disease especially need to know this fact. Not with standing this particular fact doctors should always advise patients about their prognosis by using readily available individualised prognostic charts which may offer more hope than otherwise assumed.

Patients and GPs can contribute to survivorship surveillance

It is a known fact that patients (and their partners) responding to their intuition detect more than 50% of all cutaneous melanoma. In addition up to 75% of recurrences are initially detected by patients’ awareness rather than at a doctors’ assessment. So patients can contribute immensely to their own surveillance providing they are educated about the probable benefit of so doing, and the education of the treating medical practitioner of the importance of patient observations. This knowledge can potentially make patients feel empowered and truly involved in their own care.

We also know GP’s with specific training in total skin examination and dermoscopy can develop extremely high levels of skill for melanoma detection to add to their holistic care. As an asde, the management of thin melanoma is entirely within the scope of a GP skill set. Current evidence shows no survival benefit from intensive investigation or oncological assessment for the 95% of survivors with stage one disease.

All of this means melanoma offers an opportunity to meet survivor’s needs with low-cost care in the geographic location of the patient conducted by their regular general medical practitioner which may not be true for other high incidence cancers.
Patient input to needs assessment - Melanoma Patients Australia Survey

A needs assessment survey was developed and emailed to all members of Melanoma Patients Australia (MPA) reaching a total of 1024 potential respondents. In total 19 responses were received. The survey was structured to gain insight into their melanoma journey from a consumer perspective.

The survey questions concentrated on:

- information provision
- personal empowerment
- educational requirements of both the patient and their treating physician
- elements of shared care
- overall survivorship needs.

The information acquired assisted to develop the interventions for trial in the pilot project.

General members of MPA were surveyed to gain insight into the melanoma patients journey from the survivor’s perspective. They were instructed to answer the questions from their current knowledge base without researching the answers. The results of the survey supplemented the development of interventions for the pilot project. The survey link was sent out to all consumer members by the Chief Executive of MPA.

Members of MPA highlighted problems encountered from the patient perspective related to their personal journey and the management of their melanoma. The information gained from the survey and listed below enabled the formation of baseline data and informed the development of resources including the Personal Melanoma Diary (PMD), GP letters and education packages for this pilot project.

The survey questions concentrated on whether participants felt their own journey had included adequate information provision, efforts to personally empower them and adequate education and advice regarding treatment plans to their treating physician. Questions were directed to ascertain if shared care and supportive care had been addressed.

Analysis of the answers was conducted by reviewing percentage response data as provided by Survey Monkey as shown below:

**Management / Self-management** - Problems encountered with the management their melanoma included:

- delayed diagnosis
- variation in scheduled treatment and follow up appointments
- problems with side effects
- long way to travel to see doctors
- melanoma negatively impacting on life span.

**Supportive care:**

- not knowing what to tell family
- no one to talk to about the situation

**Information and education:**

- confusion around sun exposure after melanoma
- lack of understanding on how melanoma begins
- not knowing what may occur in the future
- knowledge of survival rate is based on information provided by a specialist although commonly supplemented by internet searches e.g.
“Was told my chance of survival was about 50/50 by my surgeon (on my insistence he tell me). I read that 35% of people with my level 3 melanoma are alive after ten years. This makes me think the chances of my melanoma reoccurring are fairly moderate.” Consumer member, MPA

Respondents informed the most useful source of knowledge from their perspective based on the rating structure: 1 - most useful through to 8 – least useful.

1. specialists
2. GPs
3. internet searches
4. nurses
5. other survivors
6. patient support groups
7. booklets
8. friends

**Literature review contribution to needs assessment**
An extensive literature review was conducted to inform all key aspects of the interventions designed for this pilot. A complete list of the literature reviewed is contained in Appendix 1.

The literature review for needs assessment focused on articles that covered:

- increasing incidence of melanoma, particularly detection of thin melanoma, thus increasing population of survivors requiring follow up
- identified the current lack of evidence based structured guidelines for follow-up
- both clinical and psychosocial need for individual follow-up programs
- importance and acceptability of involvement of the GP in the follow-up process

**Medical record audit contribution to needs assessment (obtained at end of pilot period)**
Table 2 below is derived from the retrospective analysis of the discharge letter in 100 patient files prior to the project. Percentage comparisons show that there has been a significant improvement in the documentation of information provided to doctors.

A retrospective analysis of the discharge letter in 100 Alfred Hospital melanoma patient files was completed toward the end of the project. The audit included patients seen prior to the commencement of the project. The audit results displayed in the table below provide further evidence of need for the project and outcome evidence for the pilot. Percentage comparisons show that there has been a significant improvement in the documentation of information provided to doctors.
Table 2

<table>
<thead>
<tr>
<th>Item advised to doctor</th>
<th>Prior to pilot</th>
<th>During pilot</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discharge letter</td>
<td>98%</td>
<td>100%</td>
</tr>
<tr>
<td>Staging included</td>
<td>2.97%</td>
<td>100%</td>
</tr>
<tr>
<td>Thickness included</td>
<td>0%</td>
<td>100%</td>
</tr>
<tr>
<td>Prognosis included</td>
<td>15%</td>
<td>100%</td>
</tr>
<tr>
<td>Risk Stratification factors noted</td>
<td>40%</td>
<td>100%</td>
</tr>
<tr>
<td>Surveillance Plan</td>
<td>71%</td>
<td>100%</td>
</tr>
<tr>
<td>Who</td>
<td>45%</td>
<td>100%</td>
</tr>
<tr>
<td>What</td>
<td>15%</td>
<td>100%</td>
</tr>
<tr>
<td>When</td>
<td>43%</td>
<td>100%</td>
</tr>
<tr>
<td>Supportive Care Plan</td>
<td>1%</td>
<td>100%</td>
</tr>
</tbody>
</table>

1.4 Other health service providers locally & other linkages
The pilot utilised the established linkages with two of the 9 Integrated Cancer Services (ICS), the Peninsula General Practice Network (PGPN) and Gippsland Medicare Local (GML) to guide the development of the pilot project.

The Integrated Cancer Services (ICS) are clusters of hospitals and associated health services that plan and improve services for people with all types of cancers within a geographic area.

Southern Melbourne Integrated Cancer Service (SMICS) is one of eight regionally based integrated cancer services and provides a network to improve the quality and continuity of patient care and ensures that appropriate links exist between health services to optimise patient pathways for persons affected by cancer. SMICS is pivotal in ensuring strong coordination and planning across the southern Melbourne region. SMICS member health services include, Alfred Health, Cabrini Health, Peninsula Health and Monash Health. SMICS and Monash Comprehensive Cancer Consortia have a shared governance structure that has representation from the CEOs of the four member health services, Monash University and the two associated research institutes.

Gippsland Regional Integrated Cancer Services (GRICS) was formed in October 2004 in response to recommendations by the Department of Health (previously known as the Department of Human Services) in its report Cancer Services Framework for Victoria 2002 (CSFV). The GRICS was one of nine Integrated Cancer Services established under the CSFV reform framework.

Peninsula General Practice Network (PGPN) The Peninsula General Practice Network (PGPN) is based in Mt Eliza on the Mornington Peninsula and has traditionally provided a wide range of support services for general practitioners to enable the delivery of high quality primary health services to the local community. They officially closed in February 2014.
Gippsland Medicare Local (GML)
Gippsland Medicare Local works with primary health care providers to connect them to one another and share information needed to better manage individual patients. The coordination provided helps reduce the duplication of services, identifies gaps and improve the quality and safety of health care delivery in Gippsland.

Melanoma Patients Australia (MPA)
MPA has a vision to reduce the impact of melanoma on all Australians and a mission statement which is to provide information, support, awareness and advocacy to people affected by melanoma and to become the national peak body representing the interests of melanoma patients in Australia.

Australian Melanoma Consumer Alliance (AMCA)
The AMCA is an alliance of individuals and organisations, all of which come from a consumer perspective wishing to provide the consumer view and related input into research, advocacy, prevention and the general care of patients with melanoma. It does not have an exclusive membership and wishes to take an inclusive approach to all of its activities incorporating organisations such as, the Melbourne Melanoma Project Consumer Reference Group (MMP-CRG), Melanoma Patients Australia (MPA), ANZMTG, Melanoma Institute Australia (MIA), and Melanoma WA (MWA).
Section 2: Project – survivorship model

2.1 Aim/s and objectives

This project aims to develop a model for long term care of survivors of malignant melanoma, which incorporates patient self-management; general practice/specialist shared care; continuous supportive care screening; patient and family centred long term care planning; and electronic reminders.

Expected project outcomes:

1. development and implementation of a risk stratified shared care model for long term recurrence and malignancy monitoring and clinical management
2. implementation of consumer and primary care education programs utilising sustainable modalities
3. implementation of a secondary prevention and early detection of malignancy program. This program will be in accord with published guidelines and the patient management framework
4. empowerment of survivors to be active participants in their ongoing care
5. communication of lifestyle modification to minimise secondary melanoma and metastatic disease
6. development of a continuous supportive care screening and care delivery program
7. development and implementation of an electronic call back mechanism to reduce loss to follow-up
8. development of guidelines for follow-up of melanoma survivors in collaboration with Australian Survivorship Centre and publication on website
9. maintain or improve patient satisfaction with an adapted follow-up care model and follow-up guideline compliance

2.2 Pilot model

The pilot focused on:

- survivor self-management and empowerment
- continuous supportive care screening
- survivor and family centred long-term care planning
- electronic self-examination and supportive care screening reminders

Resources developed to support melanoma survivors participating in the pilot included:

- personal melanoma diary
- risk stratified shared care treatment and surveillance pathways
- automated electronic self-examination and supportive care reminders

The intentions of the interventions developed for the pilot were to:

- emphasise and enhance patient education regarding diagnosis, prognosis, self-management and self-examination according to an individual’s specific risks
- foster shared care collaboration between general and specialist medical practitioners and hospitals
- embed supportive care screening in all surveillance plans not just for those patients expressing emotional/psychological concerns at the time of discharge from acute care

Pilot project process

Project staff worked with the VMS clinic coordinator to determine the patients likely to be discharged from care that day. A set of documents were prepared for each patient. (patient information and consent form, letter to doctor, Personal Melanoma Diary, education materials).
While waiting to be seen by medical staff these patients were approached and advised of the existence of the project and were invited to have the details of the pilot project explained to them. If they agreed, project staff discussed the project comprehensively and provided them with the patient consent and information form (PCIF). If consent was declined the patient was advised that no further contact would be made and the discharge letter generated from the VMS would be sent to the referring doctor. Following this discussion, potential participants had further time on their own to read the documents and consider their willingness to consent to participate prior to their clinic appointment. If they were willing to participate, written consent witnessed by project staff was completed.

As part of the discussion patients were advised that if they provided consent they would be asked to:

1. complete questionnaires
2. complete education programs regarding melanoma and examinations of their own skin
3. attend medical consultations for their surveillance according to a protocol advised by the VMS doctor that are in accord with risk stratified evidence based practice guidelines
4. complete a written record retained by themselves of all events related to their melanoma management to facilitate transition between treating practitioners and enhance their own understanding of decisions and events in their care
5. agree that their contact details and any medical information relevant to the management of their melanoma will be kept on a secure database
6. accept periodic contact from the project investigators during the timeframe for this project being up to a maximum period of 12 months
7. provide written consent for project staff to access and use personal and health information

Following discussion with the patient project staff ensured that the medical staff caring for the patient carried out all the interventions formed as part of the pilot. The medical staff discussed with the patient, who was going to provide ongoing care and documented contact details. The medical staff filled in the relevant parts of the letter to be sent to the follow up doctor. The letter detailed disease information regarding thickness, stage, recommended schedule for total skin examination, lymph node assessment, clinical photography and ultrasound. This letter, and a copy of the PCIF, was sent to the nominated doctor separate to any correspondence forwarded from the hospital to referring and community doctors by project staff.

The personal melanoma diary (PMD) was introduced to the patient and the medical staff recorded information regarding melanoma thickness and stage of disease. Education on the importance of self-skin examination and lymph node palpation was provided. The treatment and surveillance plan section of the PMD was then completed as a joint process by doctor and patient, including discussion regarding the type of examinations and whether photographic assisted surveillance and investigations were to form part of the ongoing care plan.

At 3 months, 6 months, 9 months and 12 months subsequent to their discharge, patients were contacted according to their chosen means of telephone or e-mail to remind them of the need to carry out self-skin examination and if appropriate to see their doctor. They were also reminded to consider using the supportive care screening tool.

2.3 Evaluation plan

- Evaluation was planned using data collection via SurveyMonkey®, with participants being surveyed at 3 and 9 months into participation and general practitioners surveyed at 9 months into the pilot
- A retrospective analysis of 100 Alfred Hospital melanoma files of patients seen prior to pilot commencement was conducted to determine if the information provided to doctors had been improved
- An Access (MS) database was developed to transfer the answers in the SurveyMonkey® into a more precisely analysable form
Description of specific strategies & interventions
The overall strategy was to increase everyone's focus on the fact that specific decisions need to be made in regard to survivorship care. In particular, to verify that the patient has understood their particular prognosis, what had happened during the course of their treatment, what was needed for their further management and their particular prognosis. It was predicted therefore that patient anxiety could be reduced and that they could engage with further care fully understanding its benefits to them.

Interventions

1. The medical staff of the VMS was educated about the project and the importance of taking specific time with each patient to discuss the management of their survivorship. Junior doctors were required to seek assistance from consultants to determine the elements of the surveillance plan. Both consultants and junior doctors were educated in relation to the factors that may influence the surveillance plan. The surveillance plan was risk stratified to the extent possible utilising known factors which influence prognosis and also by a personal assessment from the medical staff as to the patients need for ongoing psychological support.

2. Specific discussion with the patient took place regarding their understanding of their prognosis, and to validate that they had fully understood the discussions that occurred during the treatment phase.

3. Specific discussion with the patient took place regarding who they wish to be involved in their follow-up surveillance. They were encouraged to adopt the shared care model with confidence being expressed in the capacity of general practitioners to carry out surveillance review. However, the final decision as to who the patient intended to see was left to the patient. Some patients were encouraged to maintain contact with specialists, when it was felt that they had a very high risk phenotype which may prove difficult for their GP to feel confident managing. Even then a concept of alternating visits between the GP and the specialist was considered.

4. VMS medical staff were required to fill in the surveillance plan document which was addressed to all medical practitioners identified by intervention 3. The medical staff then discussed the contents of the PMD in detail with the patient's so they were aware of what was in it and how to use it.

5. Project staff ensured that participants understood the need to carry out the components of their agreed surveillance plan and that electronic reminders and where necessary direct telephone conversations would be the means of contact.

The interventions were focussed at the clinical point at the end of acute diagnosis and treatment. This focus enabled codification, risk stratification and documentation of the surveillance plan to identify recurrent and new disease and simultaneously deliver this to all parties.

The tools created included:

- a precise discharge plan document to be sent to the doctors managing the survivor
- a document referred to as a personal melanoma diary (PMR) which included a summary of the information provided to the patient during acute care
- the actual surveillance plan
- education for the patient regarding self-skin examination

A further intervention was to embed continuous supportive screening into the surveillance plan by use of a validated tool included in the PMD aimed at triggering those who required emotional
support to seek help. Compliance was assisted by the use of electronic reminders to patients regarding attendance for components of the surveillance plan.

**Risk stratification**

The literature search showed that there is no clear evidence base for risk stratification that can be applied to melanoma survivorship. The Australian and New Zealand Clinical Practice Guidelines for the Management of Melanoma and acknowledge that the decisions in this regard are made by "expert opinion".

It was however shown that even in the absence of a clear evidence base of survival benefit from a particular surveillance program, patients could be risk stratified to the extent that their prognostic factors were known. Regard for this provides some indication of the potential benefit of frequent versus less frequent follow-up. It is important to note that part of the objective was to prevent over enthusiastic follow-up with the potential to increase patient anxiety and expenditure when no benefit could be demonstrated. The table below shows how these risk factors were expressed to follow-up doctors who would ultimately make the decision as to whether they would follow the VMS recommended plan or not.

<table>
<thead>
<tr>
<th>Clinical Facts</th>
<th>Histopathology Facts</th>
</tr>
</thead>
<tbody>
<tr>
<td>History of multiple primaries</td>
<td>Low risk: &lt;1.0 mm Breslow thickness</td>
</tr>
<tr>
<td>Naevi count &gt;200</td>
<td>Intermediate risk: 1.0 to 3.0 mm thickness</td>
</tr>
<tr>
<td>Dysplastic naevi count &gt;10</td>
<td>High Risk: &gt;3.0 mm: thickness</td>
</tr>
<tr>
<td>Hypopigmented primary tumour</td>
<td>Ulceration present</td>
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<tr>
<td>Body site</td>
<td>Low risk mitotic rate: = 0</td>
</tr>
<tr>
<td>Male</td>
<td>Medium risk mitotic rate = 1 to 4</td>
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<tr>
<td>Elderly</td>
<td>High risk mitotic rate: &gt; 5</td>
</tr>
<tr>
<td>Local/regional disease</td>
<td>Metastatic disease</td>
</tr>
</tbody>
</table>

**Survivorship care plans dissemination**

Survivorship care plans were directly incorporated into the information provided to the patient in the PMD and also into the letter sent to all doctors involved in follow-up. The patients were advised to take the diary to all subsequent medical practitioner visits to emphasise the planned nature of surveillance.

**Shared care with general practice**

Shared care with general practice was one of the principal aims of this project.

The methods by which this was driven commenced at the point of discharge, where patients were encouraged strongly to use their GP for follow-up rather than remain only connected with a specialist. Patients received reassurance that if their GP has an interest in melanoma surveillance they are certainly competent to perform it. The patient was further encouraged to have a direct discussion with their GP as to whether they were happy to accept this role, to learn if the GP preferred that they only remain in specialist care. Neither option was portrayed as bad, but it should have been clear to patients that it was both safe and probably desirable for them to have as much of their follow-up with their GP as possible.

One of the outcomes of these discussions was that some patients chose to see GPs who have opted to provide nothing other than skin cancer care ("skin cancer GP") rather than their regular GP. This meant the patient may have lost the holistic approach offered by full general practice when having surveillance although they were at least having surveillance closer to home.

A second approach to increasing shared care was to not burden the GP with extra work solely related to the pilot. For example, there was no requirement for them to consent to participation in the project. They were provided with the patient's information and consent document to allow
them to understand the pilot if they wished to do so. If a patient had brought their personal melanoma diary to a GP visit, there was no obligation on the GP to complete any section of it. Though the patient may have been induced to ask for investigation results or question deviation for the planned surveillance, because of its influence which may have slightly impacted GP workload. Although the model was designed to increase compliance with the protocols decided on, it was made clear to patients that they and their doctor were the final decision makers about what took place. The design of the specific letter to the doctor indicating the stage, prognosis, risk stratification factors and the specific surveillance plan was intended to subtly educate doctors regarding specialist unit expectations without implying they must abide by them.

**Governance and stakeholders**

Steering group membership was compiled to provide leadership, direction and drive the shape and trajectory of the project.

**Role**

The Survivorship Steering Group was convened to provide leadership and direction throughout the project to ensure the project objectives were achieved within budget and agreed timelines.

**Membership and structure**

- Project Oversight (ex-officio)
- Clinical Program Director, Cancer and Medical Specialties, Alfred Health
- Clinical Services Director, Cancer and Medical Specialties, Alfred Health
- SMICS Manager/Strategic Planner

**Chair**

- Louise Marshall, Melanoma Consumer Alliance, Consumer Nominee

**Steering group members**

- Dr Martin Haskett, Dermatologist, Victorian Melanoma Service (project lead)
- Mr Will Kerkhof, CEO Melanoma Patients Australia
- Mr Campbell Rose, Consumer nominee, Melanoma Patients Australia (Chairperson) TBC
- Dr John Kelly, Head Victorian Melanoma Service
- Dr Peter Briggs, SMICS Medical Director, Medical Oncologist
- Ms Merran, Tyler, Melanoma Clinical Nurse Consultant, Alfred Hospital
- Ms Josie Samers, GP Liaison Officer Alfred Health (email member)
- Dr Andrew Haydon, Medical Oncologist
- Dr Jeremy Ruben, Radiation Oncologist
- Ms Kath Ferry, Peninsula GP Network
- Ms Louise Cristofaro, Program Manager GRICS
- Ms Marg Bogart, CEO, Central West Gippsland Division of General Practice
- Dr Peter Lartner, Program Advisor, Dandenong Casey General Practice Association (email member)
- Colleen Berryman, SMICS Cancer Service Improvement Officer (Project Manager)
- Geraldine Largey, SMICS Project Officer

**Reporting**

Department of Health, Cancer Strategy and Development

**Target population/s**

All patients with a confirmed melanoma diagnosis attending the Victorian Melanoma Service were considered eligible for inclusion. Exclusion occurred when a patient met the following criteria: less than 18 years of age, non-English speaking or if judged to be incompetent to consent.
Workforce roles and engagement
The design of the pilot project did not require any reassignment of patients to alternate clinicians, or alteration to workforce roles. It did require engagement with the parties listed below which serves to indicate the members of the workforce that were aware of and part of the project.

Initially agreement was sought and received from the head of the VMS to pilot the project at the service. The unit head endorsed the implementation of the pilot and the engagement of the staff of the unit to implement the pilot. Each of the consultants and the dermatology fellows were approached individually by the project clinical lead and were provided with an overview of the pilot, including what the pilot required of them, the project objectives and desired outcomes.

It was initially thought that a nurse practitioner role specialising in the care of melanoma survivors would be developed but as the project developed it became clear that survivors are better served by limiting the number of people with whom they need to engage. The use of the functions within the PMD helped patients to feel supported and in control of their needs.

Roles created for the development, implementation and delivery of the pilot project
- clinical lead
- project manager/officers
- project researcher
- administration assistants.

Clinical Lead
The clinical lead held primary responsibility for and involvement in all aspects of the design and delivery of the project including, project development, implementation, recruitment, data collection monitoring evaluation, data analysis and evaluation. In addition the clinical lead held responsibility for the associated financial, administrative and reporting requirements.

Project Manager
The responsibilities assigned to the role of project manager entail the management of day to day operational aspects. Creation, execution and revision of project work plans to meet the changing needs and requirements while ensuring documents are complete, current and stored appropriately.

Project Manager / Officer
The project manager and officer role included the recruitment of participants, execution of and input into survey development, data collection and analysis.

Researcher
The primary responsibility of the researcher included a comprehensive literature search compilation and review compilation. Secondary aspects assigned to the role include a direct role in consenting and contacting patients while providing ad hoc assistance to the clinical Lead.

Existing roles within the VMS incorporated to execute the pilot project
- consultant dermatologists
- dermatology fellows
- nurse coordinator
- data manager
- business manager

Dermatology Consultants and Fellows responsibilities
Responsibilities of the treating doctors included completion of the GP letter outlining the disease stage, prognosis and five year survival rate. In addition they were required to document the
surveillance and treatment recommendations in the PMD to aid the comprehension and self-management of the participants.

**Nurse Coordinator**
The nurse coordinator was responsible for advising the recruiting officer of potential participants who were likely to be discharging from the clinic and entering into a shared care arrangement post discharge from the VMS.

**Data Manager**
This role provided advice on data collection and analysis

**Business Manager**
The business manager was responsible for invoicing project payments

**Engagement of other stakeholders/HSPs**
Melanoma Patients Australia
Melanoma Consumer Alliance

**Other Health Professionals involved in the pilot project**
- general practitioners and community based medical specialists
- private medical specialists in dermatology, plastic surgery radiation and medical oncology

The GP recruitment process consisted of a letter and project information from the Victorian Melanoma Service (VMS) informing the GP that their patient had consented to participate in the project. GP’s were not asked to opt in or out of the project, only to support their patent by following the management plan outlined in the letter from the VMS.

**Additional organisations contributing to the pilot project**
- Integrated Cancer Services
- Consumer Nominees
- Peak Consumer Bodies
- Medicare Locals
- GP Networks

**Organisational and structural setting**
The Victorian Melanoma Service (VMS) was established in 1994 at the Alfred Hospital as an outpatient service for patients with biopsy proven melanoma (primary or metastatic). The service maintains an active program of research in melanoma including trials of new treatments. It is a fully multidisciplinary consultative centre for the management of melanoma. Its objective is to provide a comprehensive assessment by all the specialties involved in the treatment of melanoma at a single site to achieve seamless care and a consensus management plan. It includes experts in dermatology, pathology, medical oncology, radiation oncology, general surgery, plastic surgery and psychology.

The philosophy of the clinic is patient centred. Patients are encouraged and supported to make their own decisions regarding management.

The VMS is situated within the Alfred, a major tertiary referral teaching hospital. It has a major role in the provision of specialist tertiary and quaternary services on a state-wide and national basis.
Supporting resource requirements
The supporting resources required for this project were limited to:

<table>
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<tr>
<th>Supporting Resources</th>
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<tbody>
<tr>
<td>Clinical Lead</td>
<td>Project funding</td>
</tr>
<tr>
<td>Researcher</td>
<td>Project funding</td>
</tr>
<tr>
<td>Project Manager and Officer</td>
<td>SMICS in-kind funding</td>
</tr>
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<td>Administrative Assistant</td>
<td>SMICS in-kind funding</td>
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<td>Project funding</td>
</tr>
<tr>
<td>Printing production and graphics advice</td>
<td>GRICS Funding</td>
</tr>
<tr>
<td>Electronic reminder system</td>
<td>Project Funding</td>
</tr>
<tr>
<td>Development of Active Learning Module</td>
<td>GRICS Funding</td>
</tr>
</tbody>
</table>

Clinical resources required to develop the recommended treatment and surveillance plans and associated documentation were designed to fit within the existing roles of staff employed by the Victorian Melanoma Service.

Workforce training requirements
The resources developed for the pilot were incorporated into current practice at the VMS requiring minimal workforce training to establish, implement and conduct the pilot.

The workforce training required to execute the project was limited to specific one on one information sessions delivered to the consultants and fellows of the VMS and included:

- background and pilot project rationale
- review of interventions to be applied
- education on how to add the required information into the letter to follow up doctor and the PMD
- how to provide information to the patient regarding use of the PMD

An Active Learning Module (ALM) was developed to address the increasing demands and specific GP needs for education, by offering a tailored education regarding melanoma diagnosis and survivor management to GPs suitable for use now and in the future.

Embedding of model
The pilot project demonstrated that this model can be rapidly embedded within services such as the Victorian Melanoma Service where a group approach to the task and education can be taken. Likewise, where GPs and community specialists express interest in being part of the model, it could be easily accomplished. However, such an approach will require a specific entity to be resourced to encourage the uptake of the model and time will be required within the community to explain the steps in the model.

Hypothesised intended outcomes

Patients
Increased patient empowerment and ability to be actively involved in decisions about their treatment and follow up surveillance was an intended outcome of the pilot. The interventions developed and implemented were intended to reduce anxiety by clearly and openly communicating their real situation and the supports available to best manage their survivorship journey. Enhanced patient confidence in their GP to manage their treatment and surveillance in encouraging more localised care was a key intended outcome of the pilot coupled with good self-skin examination skills.
Carers
Carers were not actively recruited to the project although they were encouraged to participate in the self-examination and supportive care screening, not only of the survivor but also conduct screening themselves. The intended outcome was to address their anxiety, leading to increased ability to support the survivor and awareness of psychological sequel which can be monitored, prepared for and dealt with. Carers and partners were also invited to complete the evaluation surveys from their view point.

Health Professional work force
The intended outcome for the health professional work force was to highlight the need for very clear information in relation to prognosis; stage, investigations and surveillance plan to enable optimum provision of melanoma follow up care in the primary care setting. Education provision highlighting risk stratification factors was intended as a key outcome.

Organisation / system
From an organisational level the intention was to assign more emphasis on discharge planning by the development of a coordinated, standardised system for information provision. In addition the development of a system for maintaining good links with patients and their treating doctors after discharge was an intended outcome.

2.3 Evaluation Plan

Key questions and methods used
The evaluation plan as outlined in the original application and work plan endorsed by the VCSP Steering Committee addressed the following objectives:

- individual participants outcomes
- uptake of program by participants
- acceptability of program participants
- effectiveness of program for participants
- acceptability to community and specialist stakeholders
- cost benefits/limitations for individual participants
- cost benefits/limitations for community and specialist stakeholders
- sustainability of the program beyond the life of the project to broader national melanoma cancer services and other tumour streams

These remained the key questions to be answered throughout the pilot project. Initial evaluation processes included electronic questionnaires and direct telephone calls to participants (patients and doctors). However, it became clear as the project progressed that for a very statistically meaningful outcome, evaluation of the base data would need to be converted into a form where the statistics of the evaluation could be managed at a much higher level. A Microsoft Access database was developed very late into the pilot by a research fellow, as an in kind contribution to the pilot project. Unfortunately due to a change in employment of the research fellow, and the retirement of the clinical lead the entry of the data to the database and its analysis stalled.

The electronic questionnaire addressed the following broad questions. The inbuilt analysis in the "SurveyMonkey ®" was used as the means of determining whether outcomes were successful or unsuccessful through measures of:

- adherence with recommended treatment plan
- use and value of melanoma diary - survivor and treating shared care team members
- use and value of self-evaluation and supportive care screening reminders
- confidence in self-management
- effectiveness of shared care
- education and information provision adequacy
- electronic call back mechanism
Resources developed/implemented to aid evaluation

Questionnaires
The project team lead by the clinical lead, structured the survey questions for the receipt of information from both the melanoma participants and GP’s. The questions were fashioned from the needs assessment analysis and the devised interventions of the pilot. Questions were structured to be specific to measure the effects of the interposition of related resources whilst incorporating subsequent open ended questions allowing for flexibility to capture verbatim responses.

Questionnaires were chosen over one on one interviews as the most likely to be effective for collection of the information required to evaluate the large number of participants in the pilot at the planned frequency. Telephone interviews were considered too time consuming and there was a likelihood that obtaining data in an ordered fashion may be more challenging. To help validate this choice, participants were asked at the time of recruitment for their preference for follow up surveys. Available choices included phone, paper based or web surveys. The greater majority of participants preferred web based methods, allowing the completion at a time most convenient to them.

Collection tool and method
Selecting the best method involved the consideration of many factors including:

- potential for automated data analysis
- provision for quantitative and qualitative data
- categorisation of information
- increase the likelihood of participant completion
- security of collected data by encryption

SurveyMonkey® was selected as it allowed for the above and also its “skip logic function” providing an option to allow participants to skip questions that were not relevant to their previous answer. It also offered enhance analysis in the form of automated charts and graphs.

Evaluation was structured to enable the analysis of forced choice structured question by calculating the percentage of respondents who selected a particular response. The open ended responses were analysed by looking for themes in the information provided.
Section 3: Project Implementation

3.1 Implementation strategy
Post consent and at the time of consultation with their treating doctor at the VMS, participants were provided with a PMD. The PMD provided information recorded by their treating doctor relating to their personal risk stratified treatment and surveillance plan, along with information on the thickness and stage of disease. During the consultation, education on the importance of skin examination was provided along with guidance on how to successfully continue to manage their disease. Instructions were provided in the diary on the type of examinations and surveillance to be conducted such as photography, lymph node palpitation, who should conduct them and the frequency of which they were required. Additionally participants were further supported by SMS and email reminders informing them to conduct their self-skin examination and supportive care screening. During the consultation a letter was also generated for the referring doctor and or the doctor nominated by the patient as providing ongoing care. The patient was then discharged from the service with shared care arrangements in place for future follow up and surveillance.

3.2 Modifications made to the model
The project team considered the project to be low risk, as participants were neither being denied access to current practices or therapies nor being asked to engage in any new treatments. However, the low risk application therefore submitted was not accepted due to the nature of the patients being considered as “vulnerable patients” because of their diagnosis i.e. melanoma and dependant on ongoing medical care. A full ethics application was required with ethics approval received on 17 December 2012. Resulting from unexpected delays in the receipt of ethics approval the decision was made not to seek multisite approval to involve patients and practitioners external to the VMS. Retrospectively contacting patient’s to conduct a value stream mapping exercise as a baseline for comparison with participants recruited to the project was also raised as a concern and therefore value stream mapping was not included in this project.

3.3 Intended and unintended outcomes (immediate)

Patients
The pilot intended to recruit 100 melanoma survivors. A total of 107 survivors were approached by project staff with 104 survivors consented to participate. Only three potential participants declined to participate, two declined without providing a reason and one person declined as they were unable to write in English. The intended implementation outcome regarding the recruitment of patients was achieved.

Carers
Carers were not actively recruited to the pilot project, although with consent from the participant were involved in the education provided regarding skin self-examinations and encouraged to assist with the task.

Health Professional workforce
The intended outcome in relation to the engagement of healthcare professionals was to establish a systematic approach to the communication of discharge planning and risk stratified follow up care from specialist to primary care providers, whilst minimising additional work load. The intention was that the specialists would have an increase focus on the survivorship phase of the participant’s ongoing melanoma journey. In particular the adequate addressing of supportive care needs and provision on education relating to participants self-examinations. A positive and unintended outcome was the introduction of documented supportive care screening of patients when attending the VMS.
Organisation / system
The intention was to support the Victorian Melanoma Service to streamline and improve the documentation of risk stratified follow up which was achieved through the implementation of the pilot. Refer to table 2.

3.4 Key learning / Insights from the implementation process

Participants
Patients discharging from the Victorian Melanoma Service back to the primary care sector displayed great interest and support in the pilot project, demonstrated by the rapid recruitment of 104 participants from 107 invited to participate within a period of 6 months.

Workforce
The interventions had limited impact on the workload of the clinicians consulting at the VMS. The commitment to improve the shared care element of melanoma survivorship demonstrated by the doctors working at the VMS was a main strength of the project. The support of the doctors to complete the management plan section of the patient diary was essential to the participant's ability to understand and manage their shared care plans in partnership with their GPs.

Stakeholder engagement
Participant evaluation was an integral component of the pilot project, the support and feedback provided by peak consumer bodies such as Melanoma Patients Australia and Melanoma Consumer Alliance proved to be a key asset in the collection of patient perspectives and greatly assisted in the development of resources. Both groups were asked to review, comment and suggest improvements to the draft version of the PMD.

It was clear from conversations with participants during the recruitment process that many were unclear what would happen to them after discharge from the VMS. These conversations also indicated patients understanding of how the objectives of the pilot addressed that fact.

3.5 Development of resources to support the model

General Practitioner treatment and surveillance letters
These were completed by medical staff at the time of discharging patients from the acute service to their follow-up practitioners. It advised that the patient had consented to participate in the pilot project and that they had been nominated as the key health professional in their follow-up management. (The patient information and consent form was enclosed for further information about the project to interested doctors).

Most importantly, the letter was designed to be a succinct easily read single page containing the crucial elements about the patient's diagnosis including:

1. disease stage: this was particularly included to encourage managing practitioners to think of their patients within an accepted framework used for management. It was hoped that this would carry through to their approach to their patient
2. prognosis: thought appropriate to ensure that GPs were advised of a precise five-year survival rate, so that no misinterpretation occurred as there is a lot of misconception and 5 year survival rate.
3. a table indicating both clinical and pathological factors that impact upon prognosis, and thereby impact on the surveillance plan. This was introduced in an attempt to commence discussion about risk stratification to community practitioners by helping them understand that not all patients faced the same risk or needed the same approach to follow-up.
This letter showed the websites where further information about disease stage and prognosis could be obtained so that doctors could be involved in the determination of these parameters for all of their patients as a matter of course.

**Electronic Reminder System.**

Several different systems were reviewed all of which work and charge for their use differently. Most of the reviewed systems required the purchase of a package including systems that were not required for this pilot. The system needed only to enable automated reminder messages for self-examination and supportive care screening to be sent by SMS, email and recorded voice messages.

The chosen system was Apptoto. Once set up it is user friendly and automatically reminded participants at the specified intervals to do their self-skin examinations and use their supportive care screening tool. The system did not require entering into a contract and did not charge set up fees. The only expense incurred was for the actual reminders sent at a cost of $20.00 per 100 reminders sent.

**The Personal Melanoma Diary**

The Personal Melanoma Diary (PMD) was developed from a compilation of the clinical experience of VMS clinicians and ideas and evidence obtained from the literature review. It was reviewed and changed after feedback from the Steering Committee and members of Melanoma Patients Australia and Melanoma Consumer Alliance. The diary was designed to be robust enough to be carried as a personal hand held record with strong plastic outers and ring binding to hold the pages together. It has simple instructions regarding use and data completion and provided education both directly and by implication as users completed the sections as to what was actually required in the follow up plan. It was also trying to represent a tangible item that patients could keep at home that evidenced they were still “in care” and had a chance to contribute to their own care. Produced in large quantities it would cost less than a few dollars. It could be made into a document to be downloaded as desired but may lose some of its physical strength were this done.

Components of the PMD include:

- personal details page, including non-melanoma related medical problems
- contact details page to identify all institutions and professions involved in the participants treatment and care
- thickness and stage
- information on risk of developing second or multiple melanoma
- recommended surveillance and treatment plans
- recommended treatment interventions
- events record and plan
- investigation summary reports page
- self-examination tool
- self-examination record
- supportive care screening tool and record
- information directory
- pockets for documents and business cards

**Active Learning Module**

The Melanoma ALM piloted between August and December 2013 was open to General Practitioners (GPs) from the Frankston, Mornington Peninsula and Gippsland region. The ALM was developed by the following organisations; Southern Melbourne Integrated Cancer Service (SMICS), Peninsula General Practice Network (PGPN), Gippsland Regional Integrated Cancer Service (GRICS); Gippsland Medicare Local (GML) and specialist dermatologist, Martin Haskett.

The melanoma active learning module was designed to up skill and further develop GPs confidence to diagnose and manage skin cancer, melanoma and survivorship issues for patients
in general practice. The ALM offered a flexible and practical learning approach with 6 hours (minimum) tailored education, consisting of three key learning activities.

**Activity 1. Online modules**

Activity 1 consisted of the two online modules developed by Cancer Council Victoria and ThinkGP. The following modules were undertaken:

- diagnosis and management of non-melanoma skin cancer
- diagnosis and treatment of melanoma

**Activity 2. Clinical placement**

Participants had a supervised clinical placement and mentoring program with a local Dermatologist or Plastic Surgeon specialist.

**Activity 3. Reflective WebEx seminar**

Participants came together in an online WebEx discussion, to reflect and share a recent account of managing a patient with melanoma in their practice. A group discussion ensued regarding best practice management approaches to care and survivorship needs.

**Learning objectives:**
On completion of the Melanoma ALM GP participants were expected to be able to:

- describe the diagnosis and optimal management including the implications and risks of common skins cancers and melanoma in their own practice
- identify clinical and histo-pathological features of skin cancer and melanoma lesions indicating the need for specialist referral
- describe the diagnosis and management of common skin cancers and melanoma
- empathically discuss and outline the process of achieving an accurate prognosis / diagnosis of melanoma including its results and staging information with patients
- use appropriate referral pathways, current resources, services, support networks, treatment options and available support from treating specialists and recommend these to a person living with melanoma
- outline a systematic approach to skin cancer prevention including the full skin examination, patient education and self-management

Eight GPs were recruited to the Melanoma Active Learning Module (ALM) from the Mornington Peninsula and Gippsland regions.

**3.6 Workforce training and education**

A GP education/feedback session was conducted at the Gippsland Regional Integrated Cancer Service Annual Forum. The learning objective of the presentation was to increase awareness of the fact that survivorship is a critical issue to be addressed and that there was a project which was aimed at increasing general practitioners participation in survivorship care. The objective was to introduce GPs to the concept of risk stratified and shared care management of survivorship.

Members of the VMS were educated via a presentation at the multidisciplinary clinic meeting followed by one-on-one review of the doctor's letter and personal melanoma diary with each of the staff actually responsible for discharge.
### 3.7 Communication strategies

<table>
<thead>
<tr>
<th>Stakeholder group</th>
<th>Meetings</th>
<th>Progress reports / briefings</th>
<th>Updates (verbal and email)</th>
<th>Presentations</th>
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</thead>
<tbody>
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<td>Project Steering Group</td>
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<td><strong>PEAK BODIES / OTHER ORGANISATIONS</strong></td>
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<td>Medicare Locals –</td>
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<td>• Peninsula GP Network</td>
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<td>• Gippsland Medicare Local</td>
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<td>• Cancer Foundation Victoria</td>
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<td>• Skin Cancer College of Australasia</td>
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<td>• FCIC conference</td>
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<td>• Melanoma Patients Australia Symposium</td>
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<tr>
<td>• ACD AGM Sydney May 2013</td>
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Communication included:

- periodic advice regarding progress to all project stakeholders
- advertising in general practitioner media advising that the project was taking place and calling for their participation in the active learning module
- presentations at the monthly forum of the skin and Cancer foundation Victoria on two occasions to advise the dermatologists of the projects existence and work
a 20 minute presentation entitled “More than Just Margins” at the Australian Skin Cancer Congress at the Gold Coast regarding the aims of the project and a request for skin cancer GPs to become more involved in consideration of survivorship issues. The potential audience was 200 GPs practising exclusively in skin cancer medicine of which approximately 80 attended. Anecdotal evaluation suggested that the aims of the talk were met.

presentation delivered by Dr Martin Haskett, Project Lead and Dr Sarah Hannam, Dermatology Fellow and pilot project researcher at the Skin and Cancer Foundation Victoria. A 30 minute presentation delivered to approximately 50 Victorian dermatologists and trainees.

a poster presentation, Melanoma Shared Care: A tripartite approach to survival on 19 May 2013 at the Australasian College of Dermatology Annual Scientific Meeting

3.8 Sustainability strategies

A sustainability strategy drove all the interventions of this pilot project. It was intended that normal practice methods and funding would be altered, rather than new structures put in place.

Whilst this overall strategy was successful, for the project interventions to be truly sustainable, there is a requirement for a coordinating body such as the Integrated Cancer Services to carry forward the education of medical practitioners at all levels relating to the implementation of survivorship activities.
Section 4: Evaluation Results - summary

4.1 Aim/s and objective/s
As previously reported in section two this project aimed to develop a model for long term care of survivors of malignant melanoma, which incorporates patient self-management; general practice/specialist shared care; continuous supportive care screening; patient and family centred long term care planning; and electronic reminders.

4.2 pilot project local evaluation
As per section 2.3 the evaluation plan as outlined in the original application and work plan endorsed by the VCSP Steering committee addressed the following objectives:

1. individual participant outcomes
2. uptake of program by participants
3. acceptability of program for participants
4. effectiveness of program for participants
5. acceptability to community and specialist stakeholders
6. cost benefits/limitations for individual participants
7. cost benefits/limitations for community and specialist stakeholders
8. sustainability of the program beyond the life of the project to broader national melanoma cancer services and other tumour streams.

Evaluation methods
- Evaluation was planned using data collection using SurveyMonkey® with participants being surveyed at 3 and 9 months into participation and general practitioners surveyed at 9 months into the pilot.
- A retrospective analysis of 100 Alfred Hospital melanoma files of patients seen prior to pilot commencement was conducted to determine if the information provided to doctors had been improved.
- An Access (MS) database was developed to transfer the answers in the Survey Monkey into a more precisely analysable form.

SurveyMonkey® was selected as the preferred data collection tool as it offered enhanced analysis in the form of automated charts and graphs and provided a “skip logic function” enabling participants to skip questions that were not relevant to their previous answer. Therefore, responses were not entered for each of the survey questions. Additionally some respondents may have chosen to not provide a response to a particular question.

A response rate of 42% (44) was achieved for the first round and 32.7% (34) achieved for the second round of survivor participant evaluations. Individual identifiers were not allocated and SurveyMonkey® records de-identified responses, meaning round one and two data could not be matched. The open ended responses were analysed by looking for themes in the answers

Individual participant’s outcomes

The majority of respondents in both rounds of data collection indicated that they were following the risk stratified treatment and surveillance plan recommended with only minimal divergence noted relating to frequency in the areas of self-examination and attendance at follow up appointments within the recommended timeframe.

Personal utilisation of the diary was high, with 77.3% (34) utilisation recorded in round one and 82.4% (28) in round two.

Round one data indicated that 56.8% (25) respondents regularly took their diary with them to all of their follow up appointments and 15.9% (7) only sometimes took their diary with them. Round two data indicated 55.6% (15) attended appointments with their diary and 33.3% (9) only taking the diary with them sometimes.
The usefulness of the melanoma diary increased over time. Round 1 responses were rated as very useful 26.8% (11), somewhat useful 41.5% (17), not very useful 24.4% (10), not at all useful 7.3% (3). Round two responses regarding the usefulness of the diary rated as follows, very useful 45.5% (15), somewhat useful 39.4% (13), not very useful 9.1% (3) and not at all useful 6.1% (2). Those who found the diary not very useful in the collection of data in round one 24.4% decreased to 9.1% in the second round of data collection, illustrating an improvement in the perceived usefulness of the diary over time.

Those that found the diary not at all useful remained relatively the same in both rounds of data collection with some comments received indicating that they had understood their prognosis was extremely good and did not wish to invest further time in the diagnosis.

The pilot led to increased demand for what may be termed an “active” electronic medical record that goes beyond recording the past and becomes an interactive tool that self populates with information, education links, plans and protocols according to entered data and ensures what is planned is what happens with all involved parties having access to the same set of information.

Acceptability of program participants
The acceptability of the pilot project and associated interventions was evident from the commencement of participant recruitment. Of the 107 people invited to participate only three declined. 45 participants responded to the first round of evaluation and although 32% of the 45 respondents indicated that they did not find the diary useful all 45 respondents (100%) indicated that they wanted to continue using the interventions and continue to participate in the pilot project.

Evidence to support the acceptability of the program in the area of general practice is inconclusive as the response to surveys was minimal and requires further follow up to provide a true and measurable result. All 104 participants nominated the GP they chose to see as part of the shared care arrangement. All of the nominated GPs were sent the evaluation survey although only six survey responses were received. However, the acceptability of the Active Learning Module was proven by seven of the eight participants agreeing that the learning objectives outlined in the module were completely met and that they would recommend the education program to their colleagues.

Effectiveness of program for participants
Responses from patients regarding the effectiveness of shared care were evenly split 50/50 in the first round of data collection and increased by 26% in the second round favouring the effectiveness of shared care. Similar to other interventions of the pilot, the longer the interventions were in place increased the effectiveness participants assigned to them.

The information and resources provided to participants to assist them to be empowered and to be actively involved in their self-management were highly valued with only a single respondent indicating that they were not valued.

Participants indicated that the health care professionals who most commonly referred to the diary during follow up were GPs, closely followed by dermatologists and then GPs with a specific interest in Melanoma.

Cost benefits/limitations for individual participants
Although a formal cost analysis was not conducted, the risk stratified pathways and recommended treatment and surveillance plans were devised to reduce over investigation and the economic impact on both the individual and the health service system.

Cost benefits/limitations for community and specialist stakeholders
These measures are economically sustainable with potential for cost savings if GP resources are used more effectively. They can be implemented and disseminated even in the absence of randomised control trial evidence of benefit, if enthusiastic individuals and groups pursue it as “good medicine”.
Sustainability of the program beyond the life of the project to broader national melanoma cancer services and other tumour streams

Overall, the pilot has demonstrated that shared care is achievable in melanoma survivorship with simple measures and that patients will engage with post-acute care.

4.3 Issues and challenges with the evaluation

General Practitioners were informed of their patient’s participation in the pilot project and that they had been nominated by the participant as the doctor responsible for the management of their survivorship. General Practitioners were not asked to consent to participate. The letter sent to the General Practitioners advising of the pilot simply sought their cooperation in the survivorship management and informed them that they would be contacted towards the end of the project to seek comment from their perspective relating to the interventions applied by the pilot.

Although varying methods were used, phone, fax and email, very few responses were received from general practice, resulting in inability to truly assess the effectiveness of the interventions.

4.4 Overall assessment of pilot model of care

Risk stratification

The risk stratification model was designed to increase compliance with the protocols. It was made clear to patients that they and their doctor were the final decision makers about what took place. The design of the specific letter to the doctor indicating the stage, prognosis, risk stratification factors and the specific surveillance plan was intended to subtly educate doctors regarding specialist unit expectations without implying they must abide by them.

The overall compliance with the risk stratified follow up treatment and surveillance schedule as indicated by participants implies that it was both useful and successful.

Survivorship Care Plans

Participants were provided with a survivorship care plan in the form of a personal melanoma diary (PMD). The PMD includes a comprehensive risk stratified follow up care plan, encourages regular self-skin examination and includes a validated self-administered supportive care screening tool. The PMD was intended to help the patient feel there is structure to their survivorship, providing emotional benefit. The diary was designed as a personal hand held record to be updated mainly by the participant but also contained clinical information populated by the treating doctor at the time of participant consent.

Shared Care with General Practice

Responses received from participants clearly indicate that shared care is valued and the value of that arrangement increased the longer the shared care plans were in place.

Participants reported the benefits of shared care plans from their perspective as providing them with confidence. Confidence that their follow up care is being adequately managed and the chances of something being missed during surveillance is lessened due to more than one practitioner involved in their follow up care.

“A second opinion is always welcome and may be helpful. It’s always possible for a Doctor to overlook or miss something and for the other to pick it up. That’s how my melanoma was discovered.” Pilot project participant

“My GP provides ongoing knowledge…Having a dermatologist in addition is important because the GP is not a specialist in this area and therefore a combination of the two gives me confidence.” Pilot project participant
Section 5: Sustainability considerations

5.1 Sustainable aspects of the pilot model

1. The embedding of the principle of shared care is entirely sustainable in melanoma survivorship. It is already happening to some extent, and needs only to be formalised extended and recognised. Accompanying education programs would be needed to ensure success, by making certain that everyone understands the capabilities of appropriately trained general practitioners.

2. The PMD can be easily provided to those in the community likely to manage melanoma patients including dermatologists, plastic surgeons, general surgeons and GPs with a skin cancer medicine interest. These practitioners could be educated to see this resource as a means of formalising the counselling of patients after diagnosis. It would also serve the purposes of the patient management frameworks in terms of standardising the care offered to individuals.

3. An electronic reminder system based around a protocol driven surveillance plan could be included within existing electronic reminder systems used by medical practitioners, into a national electronic medical record, or by institution/organisation based servers (e.g. Alfred Hospital, SMICS) with minimal modification at low cost to existing systems.

4. With further study and refinement nationally agreed risk stratification protocols of management could be formulated. An education program to get practitioners to "buy in" is also required for this to become part of standard practice.

5.2 Requirements to ensure sustainability

The major resource required for sustainability is a coordinating group/institutions/organisation that is prepared to take responsibility for refining the personal melanoma diary, the risk stratification, and the surveillance plan protocols. The same body would be responsible for reaching individual practitioners with higher education programs planning to see in the meditation by more practitioners on a progressive basis. VMS is well placed to take on this state-wide role.
Section 6: Potential scope for extension / spread of survivorship care

6.1 Application to other cancer types and clinical sites

Other cancer types
The fundamental notions of good discharge planning and patient education apply to all cancer types.

Other clinical sites
The interventions used in the pilot project could be immediately adopted by all other centres providing multidisciplinary care to melanoma patients at the point of discharge of their patients, and also could be used on a case-by-case basis wherever melanoma patients are being managed.

There is no theoretical or practical reason why these interventions cannot be taken up wherever melanoma survivors are reaching the clinical point of completion of acute care.

6.2 Work flow / key steps for adoption of model
Others wishing to adopt this model need to become aware of the literature, survey and documents created within this project. There is a need for acceptance of the benefit of GPs being responsible for ongoing patient monitoring.

Section 7: Next steps for project locally
The major step to be taken is for the project to undergo further design changes to allow more rigorous statistically valid evaluation of the interventions against the objectives. Firstly, in regard to survivors emotional and psychological wellbeing and secondly achieving adherence to patient management frameworks for survivors across the state. This could be evaluated over a relatively short period of time (possibly two years). This should be long enough to demonstrate a benefit in a randomised trial with a cohort of several hundred participants. Any survival benefit (in terms of increased duration of life would take much longer (up to or beyond 10 years).

Refer also to section 9 Recommendations

- refine evaluation process with GP’s.
- facilitation of a Webex session with GP’s similar to that of the ALM. This session would comprise of an education session to provide information to assist GPs in their follow up management of melanoma patients and simultaneously gain feedback on the provision of the risk stratified follow up developed as part of the project
- refinement of risk stratification and surveillance plan protocols
- refinement of the personal melanoma diary contents and completion process so it can be reprinted in a second edition or provided electronically for distribution to relevant parties
- education of other principal melanoma multidisciplinary management sites (Peter McCallum Centre, Royal Melbourne Hospital, Austin Hospital) about the principles of the pilot and the notion of shared care to determine whether they will be prepared to engage with it. One of the important principles to be established with these organisations is that they undertake discharge of patients to general practitioners when there is no demonstrable value in periodic review within the institution
- continued collection of melanoma survivorship related literature and data
Section 8: Overview of project impact / Conclusion

The introduction of a tripartite, shared model of care for survivors of primary melanoma will result in:

- improved patient and carer experiences
- improved clinical outcomes relating to reduced stage of recurrent disease presentation and survival
- reduction in health care expense.

1. Patient surveys gave evidence to improved patient and carer experiences
2. Improvement in clinical outcomes are not assessable in the pilot time frame
3. Reduced reliance on acute health care services has been evidenced, however the financial impact on shifting care to the primary care sector was not able to be assessed in this pilot

8.1 Impact / value

The impact of this pilot project on the participants involved via the VMS would be regarded as high, considering the attention drawn to survivorship management within a service which indirectly manages a very high number of newly diagnosed melanoma patients in Victoria.

The impact of the pilot project on work practices outside of the participant recruitment group would be assessed as minimal. However, a relatively low-grade expansion of the pilot project to all melanoma management multidisciplinary sites in Victoria could lead to a high impact very quickly.

8.2 Key learnings from participant evaluation

Survivorship care plans are utilised and valued by melanoma survivors

“It provides a medically sound and structured approach to dealing with the ongoing monitoring and treatment.”

“Good organizational tool, a reminder that I can always contact someone if I have questions or worries regarding my condition and a reminder to do the self-examinations and skin check with the doctor.”

“It makes me confident that I have a strategy and that I am not totally reliant on GPs and not overusing a specialist.”

“The diary and plan provide excellent reference material for care plans and ensure good compliance.”

Concordance with the risk stratified pathway was high

Participants generally followed skin examinations schedule. Only four respondents indicating that they were not conducting skin examinations as per their treatment and surveillance plan.

Supportive care screening was useful and utilised by participants as needed
The checklist is helpful in detailing a range of lots of factors that affect a person at any time, but especially when you are feeling vulnerable.

“I read through the supportive care tool and I did not feel the need to complete it. My distress level is low now.”

“Very supportive, but for me I do not have any problems … I have plenty of help and support as I need it.”

“I have not filled in any of the forms on supportive care, at this stage none of that is a concern for me. Also I have no emotional problems and I feel that I am in a very good place.”

The checklist is helpful in detailing a range of lots of factors that affect a person at any time, but especially when you are feeling vulnerable.

**Shared care is acceptable and embraced by melanoma survivors**

“I live in a rural area and not all areas of medical expertise are available locally. To be able to visit a specialist for skin/node checks has given me confidence that should anything further develop it will be discovered early. Shared care is peace of mind. Hopefully nothing will be missed with us all keeping tabs on my skin.”

“It makes me confident that I have a strategy and that I am not totally reliant on a GP and not over using a specialist.”

“It provides a medically sound and structured approach to dealing with the ongoing monitoring and treatment.”

### 8.3 Policy and system level questions

- Careful discharge planning which is highly conscious of the patients need for ongoing support could be extremely useful to them
- Written advice of details of diagnosis and the formalisation of a survivorship plan can be beneficial
Section 9: Recommendations

1. The interventions of this pilot should now be tested by expansion into a full formal study of the interventions by the recruitment of the other multidisciplinary care sites within Victorian hospitals, and the recruitment of community practitioners of particular interest in melanoma management. This would include a full statistically-based evaluation of the interventions and their periodic review and alteration according to patient feedback.

2. The active learning module for melanoma should be reviewed and improved, and offered across all general practitioner education groups in Victoria. To the immediate benefit of melanoma survivors, the expansion of survivorship projects and interest throughout the entire melanoma survivorship community.

3. Extend time frame to determine clinical outcomes

4. Conduct cost benefit analysis

To facilitate this happening it is recommended that the Steering Committee reconvenes with the inclusion of:

- a new clinical lead appointed from within the dermatologists of the VMS
- a representative from the psych-oncology group to add expertise re continuous supportive care methodology and assessment.

This Committee consider how to proceed to implementation including any or all of the following steps:

- Run a focus group of participants to re-question them face to face about their experience particularly with a view to refining the contents and format of all the interventions of the pilot.

- Run a focus group of newly diagnosed non participants to initially determine their view of their needs and then to introduce the interventions and obtain their views.

- Run a focus group of community based specialist and general practitioners (i.e. those not currently involved in melanoma MDT care) known to have high likelihood of diagnosing patients with melanoma and discuss the interventions with them.

- Convene the staff and networks of the integrated cancer services state-wide to understand the interventions and consider how to implement them.

- Convene the medical staff of all MDTs in Victoria managing melanoma to understand the interventions and consider how to implement them

- Support a specific research fellow at the VMS to monitor and analyse the literature for relevant knowledge with a focus on improving the evidence base for risk stratification timing, locale, content and frequency of survivorship follow up.
EVALUATION PLAN

Define the purpose of the evaluation

Evaluations are usually time-limited and with a ‘whole of program’ view. It may focus on processes, impacts or outcomes of the project/program. Match the purpose of the project to the right type of evaluation: Is the main reason to:
- Improve or refine an existing program?
- Ensure accountability by reporting to ‘investor’s or managers’?
- Measure progress towards achievement of objectives and outcomes (appropriateness)

Project evaluation will use a Program Logic approach and key performance indicators will be developed to monitor and evaluate each component of the Melanoma shared care, a tripartite approach for survival! The patient, their GP and their specialist program including:

- individual program participants outcomes
- uptake of program by participants
- acceptability to program participants
- effectiveness of program for participants (measurements against individuals baseline)
- acceptability to community and specialist stakeholders
- cost benefits/limitations for individual participants
- cost benefits/limitations for community and specialist stakeholders
- sustainability of the program beyond the life of the project to broader national melanoma cancer services and other tumour streams

Evaluation sources will include data collection and stakeholder interviews at key points of the project.

When will the evaluation be conducted?

This decision will relate to the purpose of the evaluation:
- Will the evaluation be used to inform decisions to proceed and support budget priority decisions (ie pre-program)?
- Will it be used to monitor project performance and identify possible improvements (ie during program implementation)?
- Will it be used to assess achievements of the project or program objectives, inform and improve policy (ie post-program)?
The evaluation will be developmental to inform the program design and formative whereby evaluation will developed in parallel to the program allowing reflection, review and improvement of the program as it progresses.

The findings of the evaluation will also:

- Monitor and identify the need for change to the program developed
- Measure the program successes and achievements
- Demonstrate options and support sustainability beyond the project

Who will need to be involved in the evaluation?
Who will you involve in this step (eg: decision-makers, providers, clients, etc)?

The project lead and steering group will be involved in all aspects of the evaluation.

Who should conduct the evaluation?
An evaluation can be undertaken by a contracted external evaluator or by an internal project manager. Internal evaluators will generally have a deeper understanding of the program context, so it is more likely that organisational learning will occur. External evaluators may be perceived to be more objective in their approach to the program and so offer potentially greater credibility.

Will the evaluation be done by an internal or external evaluator?

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<tr>
<th>Will the evaluation be done by an internal or external evaluator?</th>
<th>Internal evaluators – project manager and steering group.</th>
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Are there particular areas of expertise required (eg: statistical, economic)

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<th>Are there particular areas of expertise required (eg: statistical, economic)</th>
<th>SMICS will lead project evaluation.</th>
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Have you checked any business rules regarding use of external consultants?

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<th>Have you checked any business rules regarding use of external consultants?</th>
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Conducting the evaluation and deciding recommendations
How will you conduct of the evaluation and monitor the progress?

What information, data collection and evaluation methodology will provide the right evidence to best inform the people making decisions based on the evaluation results?

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<th>What information, data collection and evaluation methodology will provide the right evidence to best inform the people making decisions based on the evaluation results?</th>
<th>Evaluation sources will include data collection (as per measures below) and stakeholder interviews at key points of the project. The steering group to identify validated evaluation tools.</th>
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What measures will you be using to assess evidence of change related to the projects objectives and activities?

**Please consider what baseline measures are required to enable robust evaluation and evidence of change.**

**Please consider process, impact and outcome measures**

| What measures will you be using to assess evidence of change related to the projects objectives and activities? | Key performance indicators will be developed to monitor and evaluate each component of the Positive Change for Life program including:  
- Individual program participants outcomes  
- Uptake of program by participants  
- Uptake of program by General Practitioners  
- Acceptability to program participants  
- Effectiveness of program for participants (measurements against individuals baseline)  
- Acceptability to community and specialist stakeholders  
- Cost benefits/limitations for individual participants  
- Cost benefits/limitations for community and specialist |
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### Victorian Cancer Survivorship Program 2011-2013

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<th>Stakeholders</th>
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<td>• Sustainability of the program beyond the life of the project.</td>
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<th>Have you ensured that any requirements for program providers to supply evidence or participate in evaluation processes are part of the guidelines or contract?</th>
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<tr>
<td>The steering group terms of reference will include responsibility for evaluation.</td>
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<th>How does the evaluation connect to project monitoring and reporting?</th>
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<tr>
<td>The evaluation findings will be reported and define report scheduling to all stakeholders.</td>
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<th>Have you considered if there are ethical dimensions to the planned evaluation</th>
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<td>An Alfred Ethics Committee submission will be developed.</td>
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### How will you assess whether the evaluation meets its intended purpose?

**Is the evidence credible for decision making? Did the evaluation accomplish what it was designed to do?**

Measurements can be monitored and reported as required. Defined outcomes and outputs are achieved within agreed timelines and budget.

### Disseminating and using the results

**Timely availability of results of the evaluation will maximise the impact of the evaluation on decision-makers. Evaluation reports should be timed to fit in with government planning and resource allocation processes. Will the evaluation be formally published? How will it be used to inform future projects or programs?**

Results including achievements and challenges will be reported and published as per the communication strategy.
General Practitioner Proforma

Your patient NAME volunteered to participate in the Enhancing Melanoma Project and has nominated you as the doctor responsible for the management of their survivorship. This letter is to seek your cooperation in that process.

Your patient is currently at clinical stage .......... with a prognosis including a 5 year survival rate of ................. See: http://www.cancerstaging.org/staging/posters/melanoma8.5x11.pdf

http://melanomaprognosis.org

Further facts relevant to them which modify the follow up recommendations include:

<table>
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<tr>
<th>Clinical Facts</th>
<th>Histopathology Facts</th>
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<tr>
<td>History of multiple primaries</td>
<td>Low risk: &lt;1.0 mm Breslow thickness</td>
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<tr>
<td>Naevi count &gt;200</td>
<td>Intermediate risk: 1.0 to 3.0mm thickness</td>
</tr>
<tr>
<td>Dysplastic naevi count &gt;10</td>
<td>High Risk: &gt;3.0 mm: thickness</td>
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<tr>
<td>Hypopigmented primary tumour</td>
<td>Ulceration present</td>
</tr>
<tr>
<td>Body site</td>
<td>Low risk mitotic rate: = 0</td>
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<tr>
<td>Male</td>
<td>Medium risk mitotic rate = 1 to 4</td>
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<tr>
<td>Elderly</td>
<td>High risk mitotic rate: &gt; 5</td>
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<td>Local/regional Metastatic disease</td>
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Based on the current evidence base for the above information your patient has been recommended to:

- [ ] Carry out self-skin examination every … months and report to you any worrying lesions
- [ ] Attend an appointment with you every…..months for total skin examination and lymph node assessment
- [ ] Consider having a dermatologist or other specialist perform total skin examination alternating with your examinations
- [ ] Obtain total body photography images
- [ ] Have serial dermoscopic imaging of naevi

The project design leaves patient management decisions entirely to you and your patient, but provides you both with information regarding evidence based guidelines for their management. One of the fundamentals of the project is to foster holistic care of survivors at the local level by primary carers. Project researchers will be making contact with your patient at 3 monthly intervals to conduct a structured interview to learn what has happened to them but no comment or influence about their management will be made during that contact.

The patient consent document and detailed project description which sets out what your patient and you are requested to do is attached.

Your patient will have been provided with extra education regarding melanoma diagnosis, prognosis and treatment and the ways to manage their risk for recurrence and risk of developing further melanoma. Copies of these documents are attached to inform you what the patient has been given.

The project design does not seek to place any additional burden on you but your patient will also be given a patient held melanoma survivor’s record (diary) and may seek your input to use it. This document is designed to help the patient feel there is structure to their survivorship which will give emotional benefit. It also encourages use of self-skin examination and a validated self-
administered supportive care screening tool which is hoped will help patients seek supportive care appropriately. A copy is also enclosed for your perusal.

The project is a pilot and is funded to run until December 2013 when it will be evaluated to that date. We will write to you again at that time seeking your comments and hope you will have time to assist us with project evaluation.

Ethics approval for the project numbered 483/12 has been obtained from the Alfred Hospital Human Ethics Research Committee on 17 December 2012.

If you have any questions regarding the project please contact the Project Manager Colleen Berryman 9928 xxxx or the Principal Investigator Dr Martin Haskett on his practice phone number 9770 xxxx.

Yours sincerely

The Enhancing Melanoma Survivorship Project

- Personal Melanoma Diary as attachment
- Literature review as attachment
- Data Evaluation Report as attachment

Authorship

Dr Martin Haskett, Consultant Dermatologist (Project clinical lead)
Tracey Tobias, Manager, SMICS
Colleen Berryman, Cancer Service Improvement Coordinator (Project manager)
Dr Sarah Hannam, Dermatology Fellow (Project researcher)