‘Treatment is just the tip of the iceberg, survivorship is what lies beneath the surface.’

Victorian Cancer Survivorship Program Pilot Project
Victorian Department of Health

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The Survivorship Project team would like to thank and acknowledge Pamela Bousejean (a participant in the survivorship project) and her brother Andrew Bousejean for designing the logo and artwork for this report.
Key Messages

The Barwon South Western Region Survivorship Project implemented Nurse-led Survivorship Clinics (NLSCs) focused on improving health outcomes for survivors of cancer and meeting changing service needs. The NLSCs were provided to survivors from eight cancer tumour streams, implemented across three sites, with the potential for survivors of all cancer types to be included.

Survivorship Care Plans were developed (in electronic format) for Breast, Colorectal, Head & Neck, Hodgkins Lymphoma, non-Hodgkins Lymphoma, Brain, Bladder and Ovarian Cancers based on a common template.

Cancer services traditionally provide medically focused follow up to survivors of cancer, and this project identified the important role completed by the Survivorship Nurses in assessing present physical and psychosocial needs and future risk of longer term/chronic illness and (which may arise 5, 10 or 20 years later) and transitioning this care to Primary Care Providers (GP, GP Practice Nurses, Allied Health workers).

The survivorship service was rated highly by participants; the clinic appeared to have had a positive impact on empowerment, as well as health literacy, specifically, feeling understood and supported by health care providers, having sufficient information being able to identify good information and reliable sources of information and improving their navigation of the healthcare system.

Cancer Specialists, General Practitioners (GPs), Allied Health professionals, Cancer Nurses and Radiation Therapists reported the NLSC had improved post treatment care for survivors and had enhanced continuity of care between Cancer Specialists and General Practitioners. Acceptance for the survivorship service as an integral part of the cancer services trajectory is demonstrated by a continued high rate of referrals from cancer specialist following the completion of the pilot period.

GPs generally reported a high level of willingness to be engaged in survivorship care. One page tumour specific GP surveillance guidelines corresponding to the eight patient Survivorship Care Plans were designed and received a high level of acceptance from GPs.

A model transitioning survivors of cancer to ‘shared cancer care’ or discharge, from cancer specialist to GP, was developed and trialled. Cancer specialists demonstrated an increasing willingness to develop guidelines of shared survivorship care with General Practitioners (GPs) particularly when patients were more than 2 years post completion of treatment.

Cancer survivors participating in the project demonstrated a high level of need for rehabilitation and community services with a total of 100 referrals instigated. Aligning ‘survivorship’ with ‘chronic care’ concepts led to increased understanding, and acceptance of survivorship issues by GPs, GP Practice Nurses and Allied Health professionals.

The cost assessment demonstrates the Nurse Led Survivorship Clinic does not appear to incur many resources costs, with the main costs being attributed to Survivorship Nurse salaries.

A randomised controlled trial, involving two groups, one which receives the intervention and one which receives usual care, would provide much needed evidence for clinicians, health services and policymakers to enable them to make judgments about the true value and impact of the survivorship clinic in clinical and community settings.
Executive summary

The Barwon South Western Region Survivorship Project implemented Nurse-led Survivorship Clinics (NLSCs) focused on improving health outcomes for survivors of cancer and meeting changing service needs.

Key outcomes:
The survivorship service was rated highly by project participants. General Practitioners (GPs), Allied Health professionals, Cancer Specialists, Radiation Therapists and Cancer Nurses reported that the project had improved outcomes for survivors of cancer. A continued high rate of referral by specialists after the completion of the pilot project supports acceptance of the new survivorship service.

Key outcomes were inter-related, and will be outlined according to key project objectives.

1. Nurse-Led Survivorship Clinics
NLSCs were provided to cancer survivors from 8 tumour streams, implemented across 3 sites, with the capacity for the service to extend to all survivors regardless of cancer type. Survivors of cancer were provided 2 consultations with the survivorship nurse and the person’s GP was contacted by phone and engaged in discussion of ongoing survivorship needs.

Similar patient, professional and organisational systems and documentation were implemented across each of the 3 sites with flexibility to integrate local health service design, local knowledge and service networks. Assisted self-management and patient empowerment and education approaches were central service design and delivery.

2. Survivorship Care Plans
Survivorship Care Plan (SCP) templates were developed in the Cancer Services electronic patient records system (ARIA) for 8 types of cancer utilising a common format. Electronic capability allowed all documents including Survivorship Care Plans (SCPs) and letters to GPs to be individualised for each participant and also allowed some auto population of information, data identification and data collection. Electronic sharing of SCPs and documents to GPs continues to be pursued.

3. Access to allied health and community health services
The Survivorship Nurses identified individual requirements for allied health and community services. Overall, 47% of participants received referrals to allied health and community services indicating a considerable unmet need for these services. Allied health and community service professionals showed willingness and considerable interest in responding to participant needs and the strategy of aligning survivorship needs with existing chronic care and health prevention strategies was very successful in gaining increased understanding and acceptance of referrals. Developing a resource of cancer-specific and general health services available to survivors has occurred and continues.

4a. Coordinated pathways of care between cancer services and primary care providers.
Pathways were developed to support the transition of survivorship care from Cancer Services to Primary Care Providers (GPs, Practice Nurses and Allied Health Providers). The GP of each participant was contacted by phone (60% success rate with some Practice Nurses also contacted) and engaged in the ongoing care of the cancer survivor. Of 50 GP respondents, 96% perceived the tumour specific surveillance schedules designed for the eight tumour groups as useful in the ongoing care of patients. Aligning ‘survivorship’ with chronic care and health prevention strategies led to acceptance of survivorship issues, with transition of holistic health care to GPs ensuring a greater potential capacity for monitoring and identification of long term effects of the cancer and treatment (e.g. 10, 20 years later).
4b. ‘Shared cancer care’ between cancer specialist and GPs.
Pathways to support ‘shared cancer care’ between cancer specialists and GPs were developed and implemented for a small number of survivors within 2 years of completion of treatment. ‘Shared cancer care’ was defined as the GP completing some or all of the tests, scans and physical examinations previously completed by the cancer specialist or commencing these at an earlier time. Cancer specialists showed greater interest in sharing ‘cancer care’ or discharge to GPs where survivors were more than 2 years post completion of treatment. Referrals for 34 additional patients (more than 2 years after completion of treatment and therefore not eligible for the SNLC) were received by the project team with the project resources being trialled to support transitions of this bonus group to GP care.

5. A stratified risk assessment tool, to guide selection of appropriate levels of survivorship care.
A model was developed incorporating the factors impacting on patient level of risk. At present cancer specialists continue to assess medical risk and prefer to share ‘cancer care’ with GPs on an individually determined basis. A system utilising existing specialist to GP correspondence, the one page tumour specific survivorship guidelines and a signed GP acknowledgment and agreement to accept care was trialled. The NLSC broadens the concept of risk to include holistic needs and chronic illness, and transitions this care to PCPs and Community Health which is particularly relevant to the long term care and health of the patient.

6. A multidisciplinary clinic to provide long term follow-up for high risk survivors of cancer.
The implementation of a separate clinic for high risk survivors (of a range of cancer types) was considered and not progressed on the basis that it was not consistent with tumour stream care. High costs for staffing and resources, and the ongoing availability of a suitable clinical leader were considered to be unsustainable and unlikely to continue past the pilot project phase. The high risk head and neck tumour stream were included in the pilot of the Nurse Led Survivorship Clinic.

The work of the Survivorship Project Board, project team, key stakeholders, participants and consumer representatives, was acknowledged by the project winning Barwon Health’s Health Care Innovations Award for 2013.

Key findings:
This demonstration project trialled a systematic approach to providing a NLSC, and has offered great advantages to survivors of cancer, in terms of improving access to information and support. The NLSC carries significant potential to meet the ongoing psychosocial needs of survivors of cancer over time, by improving patients’ confidence in their ability to navigate the health care system and have control over their condition. Key findings included:

- 90% of participants reported the two consultations with the Survivorship Nurse were either ‘quite helpful’ or ‘very’ helpful; over 77% reported contact with the Survivorship Nurse would help them raise issues with their health provider and 82% reported the Survivorship Care Plan was helpful.

- Implementation of the survivorship clinic had the potential to impact on delivery of services to survivors of cancer, by improving health literacy and empowerment outcomes, as well as improved satisfaction with health service delivery following treatment for cancer.

Project Recommendations:
Outcomes of the project demonstrated that NLSCs were valued by survivors of cancer, Cancer Specialists, Cancer Nurses and Primary Care Providers. A health professional needs to take leadership in the survivorship phase, and nurse-led programs appear to do this well.
State-wide policy development, impacting at organisational levels, will aid survivorship service development. Funding to extend the project will increase survivorship skills and knowledge base, allow for further data collection, as well as potentially lead to significant medium and long term cost savings and improved health outcomes.

A nurse led survivorship service structured with a central hub, satellite clinics and outreach clinics has the potential to extend to all regions and takes advantage of central coordinated service provision and knowledge base, while allowing individual localised benefits and tailoring.

Survivorship services to all cancer groups can be delivered utilising common structures, pathways and documents but flexibility to respond to individual survivor needs, tumour specific information and community characteristics is recommended. Extending eligibility of the program to all patients successfully completing treatment and patients living with cancer (e.g. myeloma) and receiving ongoing long term treatment is recommended.

**Project expansion**

The longer term aim is to position survivorship, shared care and transition to GPs as established phases within the cancer trajectory. Objectives for the next 2 years include to provide Nurse Led Survivorship Clinics to survivors of prostate and other cancer types including lung cancer survivors and patients living long term with the impacts of cancer and cancer treatments (e.g. myeloma).

This project has achieved a considerable level of acceptance particularly given the relative newness of the initiative and will benefit from further work to embed the Nurse Led Survivorship Service into clinical practice, allow an extension of the current data base and streamlining of services to increasing efficiencies.

Business and funding opportunities will be pursued to ensure ongoing organisational funding, including preparation for Activity Based Funding (ABF) funding release in 2014/15.

Telehealth will be investigated and trialled to provide greater access across the region and align with the current Telehealth initiatives being implemented by Barwon Health.

Reducing risk, and increasing sustainability and knowledge/skill base of survivorship services is vital to ensure the ongoing capacity to forward local, regional and state wide survivorship services. The completion of the phase one Barwon South Western Survivorship Project provides for considerable consultancy opportunities and sharing of survivorship resources including to survivorship projects and initiatives in other regions.

A further trial, and audit of the transition of survivors of cancer from Cancer Services to ‘shared cancer care’ and discharge to GPs (including those over 2 years post completion of treatment) will further determine patient outcomes and offers considerable opportunity for service improvement and economic savings.

This new model of care has potential for development and real change in the delivery of services to survivors of cancer. Continuation of the NLSC to recruit and follow up 50 additional participants will contribute significantly to evaluation and economic data required for the development of a NHMRC proposal in 2015.
Project Background

Cancer survivorship is now recognised as a distinct phase of cancer care. The number of people living after completion of cancer treatment is increasing due to advances in early detection and treatment, and as a result of the population living for longer. Five-year survival from all cancers combined increased from 47% in 1982-1987 to 66% in 2006-2010.

The term ‘cancer survivor’ has been applied to a range of time points in the cancer journey. This project utilises the words ‘cancer survivor’ or ‘survivor of cancer’ to refer to people who have completed chemotherapy and/or radiotherapy and surgery with curative intent (i.e. do not require further chemotherapy or radiotherapy). Eligibility for inclusion in the pilot project was defined as survivors of cancer who had completed the above treatments for Breast, Hodgkin Lymphoma, non-Hodgkin Lymphoma, Head and Neck Cancers, Colorectal, Brain, Bladder and Ovarian Cancers within the previous two years.

‘Cancer survivorship’ focuses on the health and life of a person post cancer treatment and until the end of life. It covers the physical, psychosocial, and economic issues of cancer and includes issues related to health care and follow-up, late effects of treatment, second cancers, and quality of life. Family members, friends, and caregivers are also considered part of the survivorship experience.

The Barwon South Western Survivorship Project commenced in 2012 as one of six state wide projects supported by the Victorian Department of Health to develop and trial models of survivorship care. Led by the Barwon South Western Regional Integrated Cancer Service (BSWRICS), project partners included Barwon Health (BH), Western District Health Service (WDHS), Barwon Medicare Local (BML), Great South Coast Medicare Local (GSCML), and Deakin University (DU).

The Barwon South Western Cancer Region extends from the Bellarine Peninsula to the South Australian border covering a total area of 33,000 square kilometres. Geelong, situated in the east of the region, is Victoria’s largest regional city with Colac, Warrnambool, Portland and Hamilton being significant regional cities and centres. The regional population is 380,000 with a growth rate higher than the regional Victorian average and projected to increase to 445,000 by 2026.

Relevant regional population factors include higher than average population of retirement-aged residents, poorer health outcomes compared to some other Victorian cancer regions and lower than average health literacy, educational attainment and socio-economic levels within some areas of the region.

Regional Cancer Services

Barwon Health Cancer Services are the major cancer care provider in the region with more than 21,000 face to face doctor/patient consultations in the 2012/2013 financial year, including outreach services. Patients living across the region may travel significant distances to Geelong (the only radiotherapy treatment service in the region) and may also receive cancer treatment services locally at WDHS (Hamilton), Portland District Heath (PDH), Colac Area Health (CAH) or South West Healthcare (SWH) in Warrnambool. Patients may receive cancer care from centres in adjacent cancer regions (Ballarat) or from major metropolitan services.

The Evaluation of Cancer Outcomes (ECO) Project 2008 data highlight that approximately 72% of rural patients from the region received care from at least two different health services.

Patient needs

Australian and international research recognises that patients completing cancer treatments are often left with a range of physical, psychological, social, existential, vocational, financial and other needs.
“I wish I could fix the fatigue. At the end of the day my legs ache because they are so tired. It’s been 7 months and I just know that I can’t do anything about this. And that means I can’t return to a normal job. Because I am a different person sexually and I am on a pension and don’t bring home the money then I am not a man anymore.” (Male colorectal cancer survivor)

The US Institute of Medicine’s hallmark report (2005) placed the post treatment needs of patients firmly in the spotlight and recommended that services include intervention to address all patient needs and include coordination of care between specialists and primary care providers (General Practitioners, GP Practice Nurses, Allied Health Professionals).  

Limited reliable knowledge is available regarding the needs of the survivors of cancer in the Barwon South West Region. The 2009 PROSPECT study of patients finishing their cancer treatment found 30% reported being provided a written plan to guide their follow up care (although no care plan has been found). Percentages of patients reporting they received information were 64% for information on managing their ongoing symptoms or side effects, 34% on recognising symptoms of recurrence, 55% on staying healthy, 34% on how they might feel emotionally after finishing treatment and 61% on how to get extra support if needed. Anecdotal feedback from the region suggested survivors:

- Often feel lost and abandoned when treatment support abruptly ends.
- “I saw someone every day for 6 months and then I was told I should come back in 3 months for a scan.”
- “I think the best way to describe myself was that I was lost, I had no direction or support. I was stuck in a strange limbo in my cancer journey.”

Often report significant levels of distress on returning to the cancer centre and waiting amongst very unwell patients receiving treatment.

- “I always dread coming back for my clinic visits, it’s so busy and some people look so sick”.

Do not receive referrals to rehabilitation and support services.

- “Sometimes I think my recovery could’ve been fast tracked by 6 months had I gone to the survivorship program earlier. No one will ever know but I think maybe I would’ve spoken about my digestive problems and I could’ve been referred to a dietician, or found out earlier about the Chronic Disease Management Plan... I could’ve been on top of my health issues earlier before they got so bad and I could’ve avoided that emergency hospital admission – a cost to me and the health system.”

Do not understand how to return to good health.

- “I finally realized that I could be an active participant in my own health, especially when I started to notice the positive changes. And it was wonderful to see the results of my progress.”

Current follow up and review of cancer survivors is highly focused on surveillance for recurrence of cancer. Assistance with physical, psychological, sexual and other health needs is ad hoc and relies on patients seeking information and asking questions, which they often feel unable to do.

- “I didn’t know who to talk to about the changes to my body, I felt like I should just be lucky to be alive and should be able to just get on with it.”

Cancer Specialists’ Needs

Individual cancer specialists determine the regularity and duration of post treatment follow-up for each patient. Discussion with cancer specialists indicated that a number of patients return unnecessarily to the hospital setting for routine tests that could potentially be followed up in the community by their GP.

Cancer Service needs

With the expected growth in cancer incidence, combined with increased survival rates, Health Services need to find efficient ways to meet the initial and longer term health care needs of survivors whilst not compromising access for new patients. In an increasingly constrained fiscal environment this presents a significant challenge.
General Practitioner (GP) needs
Previous projects have identified GPs’ preference for one page documents to aid quick reference. GPs are provided with a summary letter after each specialist review appointment occurs, but report being disengaged from management of the patient’s health and suggest ongoing GP involvement at all phases. Primary Care Providers are supported by BML and GSCML who were major project partners.

Survivorship Project Model Aim and Structure
Aim: To design, implement and evaluate a model of care to improve health outcomes for survivors of cancer and to respond to changing service needs.

Project objectives
To design, implement and evaluate:
1. A nurse led survivorship service in both a regional and rural area to address the health and wellbeing needs of survivors of cancer from a range of tumour types.
2. Individual survivorship care plans utilising a patient centred approach.
3. A multidisciplinary approach to survivorship care, which utilises a full range of medical, allied health and community supports and services.
4. Coordinated pathways of care between cancer services, primary care and Allied Health providers.
5. A stratified risk assessment tool to guide selection of the appropriate level of survivorship care and follow up for each patient.
6. A multidisciplinary clinic that provides long term follow up for high risk survivors of cancer.

Governance and stakeholders. Project board members included the Chair of the Project Board, two consumer representatives, the Project Manager, two survivorship nurses, researchers and health economists from Deakin University, representatives from BSRWICS, BML, Australian Cancer Survivorship Centre (ACSC), WDHS, BH and the Victorian Department of Health (DH Vic). (Appendix 1)

Target population. People, aged over 18 years, living in regional and rural areas that had completed treatment for a range of cancer types were to be included in the project. The health needs and follow up care of survivors at high, medium and low risk survivors were to be considered.

Organisational and structural setting. Organisational and structural setting (Appendix 2).

Workforce engagement and resources. Workforce engagement consisted of a Project Manager (0.6 EFT); Survivorship Nurses at BH Geelong (0.6 EFT) and WDHS Hamilton (0.2 EFT); in kind administrative support from BSRWRICS; in kind project worker and consultation from BML (0.2 EFT); part time research assistant and health economist at Deakin University; in kind and financial support from Faculty of Health at Deakin University and an IT consultant (25 hours). Resources requirements included clinic rooms for nurse appointments, 3 workstations, access to record systems and databases.

Workforce training requirements. In the absence of a structured survivorship training program, the Survivorship Project Board provided opportunities to meet the training needs of each team member. These included conference and workshop attendance, self-directed learning and review of literature, Barwon Health professional development programs, IT training, peer review and support. Attendance at the Victorian Survivorship Community of Practice provided access to education, networking and resources.
Evaluation Plan

Key Questions to be answered. Key questions to be answered related to implementation of the project aims. Participant health literacy, quality of life and satisfaction with service delivery; professional feedback and levels of acceptance; economic costs and service sustainability were to be evaluated.

Methods. The evaluation framework comprised qualitative (interviews) and quantitative components (surveys and questionnaires). Participants were asked to complete written questionnaires prior to, one week after and again 3 months after attending the SNlC. Questionnaires included The Health Literacy Questionnaire (HLQ), Assessment of Quality of Life-8D (AQoL 8D), Health Education Impact Questionnaire (heiQ) and questionnaires designed to collect information regarding resource use, economic cost, patient satisfaction and professional acceptance and feedback.

Resources developed. A baseline questionnaire, patient satisfaction, patient resource use, health professionals and cancer specialist feedback and acceptance questionnaires, and 2 GP evaluation tools were developed for use in the project.

Project Implementation.
The project commenced in May 2012 with the first project board meeting and employment of the Project Manager. The Survivorship Nurses commenced work in Geelong in June and in Hamilton in October 2012. An extensive review of literature was undertaken. Key stakeholders included cancer specialists, consumers, BML, PCPs, administrative and medical records staff, radiation therapists and Allied Health professionals.

Resources developed to support the model. Resources developed included tumour-specific Survivorship Care Plans (Appendix 3) and GP tumour specific surveillance schedules (Appendix 4), correspondence, flyers, reports and health assessments. All resources were reviewed and/or trialled with consumers and clinicians prior to being piloted. Modifications relating to levels of content, use of professional and person-centred language and format were made before being incorporated within the intervention. (Appendix 5)

Communication strategies. A range of communication strategies were developed (Appendix 6) including an information flier and electronic newsletter. Existing BML GP and Practice Nurse Newsletters, Cancer Centre newsletter and the BSWRICS Annual Report (Appendix 7) including a consumer story were also utilised (Appendix 8). An article referencing the project in the Geelong Advertiser (28/8/13) and the project winning Barwon Health’s Health Care Innovations Award for 2013 also impacted to raise the profile of survivorship.

Workforce Education and Training. The Survivorship program provided a range of education opportunities. (Appendix 9)

Embedding of the model. The project team chose to align its work with clinical tumour streams in recognition of the existing service direction and organisational structures. Engagement and discussion with individual specialists and clinician groups identified non-Hodgkin Lymphoma and the often higher needs Head and Neck Cancer survivors as suitable groups to start the design and implementation process. Procedures, tools and documents were designed and trialled with feedback from all parties incorporated. With refinements, successful outcomes and a raised professional profile the service was rolled out in incremental steps to a further 6 cancer groups.

While ethics approval was being gained, the evaluation framework was completed, and Survivorship Care Plans (SCPs) and GP surveillance schedule templates were designed. Recruitment extended from October 2012 to October 2013 with data collection completed on 28 February 2014. Project objectives were identified and developed across a short and longer-term timeline. Intended outcomes, enablers, challenges and learnings for each objective were closely linked and for ease of reading will be addressed individually.
Objective 1. Nurse Led Survivorship Intervention

Outcomes Achieved
A Nurse Led Survivorship Clinic was establishment in three centres (Geelong, Hamilton and Colac) and expanded post cancer treatment services to include a longer term (chronic) health, wellbeing and quality of life focus. A survivorship model, guidelines, care plans and corresponding GP surveillance guides were developed for participants from 8 tumour streams with program design being suitable for application to all cancer types. Assisted self-management and patient empowerment approaches were central to service design. Participants provided immediate positive feedback regarding the nurse intervention.

“It was great to be able to talk about all of this. It has given me clarity.” (Cancer Survivor)

The project led to a significant increase in referrals (100 in total) of cancer survivors to rehabilitation, allied health and community services, with the strategy of aligning service delivery to concepts and frameworks used for other chronic illnesses, being integral to the acceptance of these referrals.

Cancer specialist acceptance has been indicated by a steady increase in referrals, continuing past the completion of the pilot period, and by specialists approaching the Survivorship Nurse (SN) with further tumour types and patients that they believed would benefit from receiving the service. The Nurse Led Survivorship Clinic was recognised as responding to the physical, psychological, social, employment, financial, sexual areas of life not normally addressed in medical review appointments.

“The survivorship clinic provides patients with information that I don’t have the time or skills to provide.” (Medical Oncologist)

Enablers
A dedicated and focused survivorship service located within the cancer centre was important in creating a presence and to gain acceptance of the survivorship phase as integral to cancer services. Identification and
relationship building with survivorship ‘champions’ (specialists, Allied Health etc.) and developing a level of professional credibility and initial success, contributed significantly to project momentum.

Promotion and discussion of cancer survivorship as a chronic disease and creating a service which complemented rather than competed with existing services was effective. The use of existing clinical systems (e.g. electronic systems and clinical meetings) increased acceptance and enhanced sustainability in a busy workplace. Educating and allowing all cancer staff (e.g. a Allied Health workers, chemotherapy, radiation and breast care nurses) to promote patient referrals, with the specialists confirming the patient’s survivorship status and suitability by way of a formal referral, allowed all staff to be engaged.

General health assessment tools and resources were tailored to provide survivorship specific tools and guidelines. The use of patient centred and motivational interviewing approaches, allowed for discussion of sensitive health issues e.g. sexuality, quitting smoking and/or unhealthy weight range.

**Challenges**

A number of patients, oncologists and nurses expressed concern that the services developed might cease when the pilot ended, resulting in some initial resistance to contribute to project development. The existing strong focus on medical follow up resulted in some clinicians having difficulty recognising that survivors might have unmet needs requiring a service.

“We already follow up patients after their treatment. We meet all their needs such as checking for symptoms and skin reactions after radiation.” (Radiation Oncologist)

Engagement of specialists individually or in groups was at times difficult due to a combination of staff changes, relatively small team sizes in regional centres, busy workloads and conflicting priorities and interests.

A major challenge to the service is the length of time required to complete individual patient centred care plans. Up to 5 hours per patient is required to complete 2 face to face appointments, summarise treatment history, contact the GP, complete the care plan and identify resources and complete referrals. Limitations to information technology in regional and rural areas impact on and reduce efficiency.

Rehabilitation and allied health care support services for patients post-treatment appear limited at Barwon Health in comparison to those potentially received by orthopaedic, surgery and cardiac patients.

**Key Learnings**

There is no one ‘correct’ time to offer survivorship services. The program should be re-offered in the period following completion of treatment as individuals vary in their ‘readiness’ to accept survivorship intervention. Survivorship ideally addresses individual concerns and questions as each person has a unique experience of cancer survivorship depending on a wide variety of factors.

“I knew I wanted to get back into life but I didn’t know how much I could do without hurting myself physically.” (Young transplant survivor)

Cancer services currently address cancer as an acute illness with medically focused follow up however cancer has a lifelong impact on both patients and carers and should be responded to as a chronic condition. It is important the survivorship phase be positioned as an integral part of the cancer trajectory and an invitation to attend the survivorship service (as appropriate) become an automatic part of the cancer journey.

Psychological distress is often given a relatively low priority during active treatment but is present as a major issue for many cancer survivors. The NCCN Distress Thermometer (Appendix 1) was found to be lacking in relevance for survivors of cancer (eg is not tailored to the treatment effects). Motivational interviewing was a valuable tool within the survivorship intervention and Mindfulness¹³ (evidence based
tool) has potential to assist with distress. Anxiety, distress and quality of life impacts were found to be as significant for carers, as for the patient.

“I am all right love, but my wife is the one who is really worried and needs your help.” (Cancer Survivor)

Provision of information at a ‘teachable moment’ when participants are considering ‘the rest of life health’ was observed to be important even if similar information may have been provided at an earlier time.

“Information on side effects needs to be provided again now. I received it before in the orientation pack but the purpose then was to inform me about treatment and consent.” (Cancer Survivor)

Inclusion of health counselling and prevention approaches in the survivorship phase aimed at avoidance of further cancers (e.g. sun protection, weight management) was successfully achieved. Smoking cessation programs are readily available, but poorly utilised, and should be more actively promoted.

“I am delighted to report that he has quit smoking! It appears he was convinced by the efforts of our survivorship nurse, and a referral to the community smoking cessation program.” (Haematologist’s letter to GP)

Rural and regional health centres and the communities in which they are based, were identified to have unique factors and challenges impacting on acceptance of the survivorship models e.g. Hamilton GP Service demonstrated a high level of willingness to engage in shared care arrangements; the satellite clinic in Colac was very well received and generated increased allied health services. Shared roles (Cancer Link and Survivorship Nurse roles in Hamilton) were successful but can challenge priorities.

A major modification early in the project was to extend the eligibility for the NLSC from within 1 year to within 2 years of participants having completed treatment. This reflected the project learning that many survivors had considerable unmet needs at 2 years or longer, after completion of treatment.

A key learning was that the survivorship nurse role requires a range of specialist skills and knowledge, and this highlights the need for development and maintenance of this skill set, and for survivorship to be included in nursing curriculum and professional development.

Sustainability
The specific survivorship nurse position is crucial in order to sustain survivorship service delivery.

“For me the big turning point in the ‘post treatment’ stage was when I first met the survivorship nurse. Without exaggeration from that point on things began to improve for me.” (Cancer Survivor)

Time spent in project development and trial stages, and then reporting on initial successes resulted in improved long term implementation, acceptance and roll out. The development of cancer specialists as survivorship ‘champions’ was key to success throughout the project and engaging in a high level of ongoing collaboration and communication with cancer care staff is essential. Listening and identifying the interests and motivations of key stakeholders aids engagement and avoids conflicts arising. Creating a ‘presence’ and attending Multidisciplinary Disciplinary Meetings (MDMs), Journal Clubs etc. increased acceptance and recognition of the Survivorship Nurse as a professional team member. Building on existing processes increases acceptance and saves time e.g. a short trial of a new and separate survivorship referral form was poorly accepted and utilised, so discontinued.

Survivorship appointments can be lengthy when patients have complex needs and high levels of distress. A focus on triage with referral onward to rehabilitation and community services was implemented successfully e.g. to psychology, counselling, and psycho-oncology. Administrative assistance, mailing appointment details and information (as compared to phone discussion) and potentially implementing a reminder system would maximise specialist survivorship nurse time use. Participation in the NLSC can be captured within RACER -Regionally Aggregated Cancer E-Repository allowing for analysis of participation against long term patient outcomes.
Objective 2. Individual Survivorship Care Plans

“I now have a folder full of lots of useful information that the nurse helped me form. It’s like my ‘go to’ book full of resources for all different things to give me a starting point if I need help with anything.” (Young transplant survivor)

Outcomes Achieved

A Survivorship Care Plan (SCP) master template was developed (utilising consumer friendly language) and enabled individual versions to be designed and trialled for 8 tumour streams. The SCPs were integrated into current electronic clinical systems (ARIA) allowing elements of electronic population and data collection, and the addition of individual information. SCPs were designed to align with and to facilitate the completion of GP Chronic Disease Management Plans (GPCDMPs)

Enablers

Aligning SCPs with the existing tumour stream approach maximised project outcomes and success (the initial generic model proposed did not recognise these). Clarifying the purpose of the care plans and the preferences of the potential users also assisted in development and acceptance. Seeking and integrating consumer and participant feedback improved outcomes. Recognising the changed needs of patients in the survivorship phase (as distinct from the diagnoses and treatment stages) and integrating a health and wellness model when developing content and design of care plans was extremely important.

“Before it was about me not dying, but now I am cured I want to live well.” (Cancer Survivor)

Challenges

Key service partners varied considerably with respect to access to communication technology, software and capacity to share information. At present there is limited access to information sharing, although the advent of the Personally Controlled Electronic Health Record (PCEHR) may assist this. Interactive shared IT platforms would allow for the creation of updated documents. At present both hard copy and electronic record systems are required with considerable time spent mailing out hard copies to GPs. A trial of transferring patient information from the main cancer centre to GPs is ongoing but has significant limitations and capacity.

Key learnings

The early survivorship period is viewed as a time to re-evaluate goals and health status, life direction and to reset priorities, but not all people can do this without support. SCPs provided the opportunity to develop a written health plan including individual goal setting which increases relevance to the individual person.

“I want to get fit enough go around Australia in my bus with my dog.”

Recognition that cancer staff may find the long term physical and psychological impacts of chemotherapy and radiation therapy confronting to list, assisted in understanding initial resistance to care plans.

Completing individual care plans is relatively time and labour intensive (e.g. collating treatment summaries involving a range of providers and sites). Maximising the use of electronic documents was successful, but requires updating, staff training and IT support.

Sustainability

Electronic recording, storage and transmission of survivorship documents increases efficiencies and integration of further IT systems available is being pursued e.g. MDMs and CHARM (the Chemotherapy and Records Management online prescribing system). Electronic programs that allow dynamic sharing of information will particularly improve service coordination.
Group led sessions or referral to group sessions\(^{15}\) may potentially provide common messages (e.g. health education) effectively and economically. The focus of increasing each participant’s confidence and skills in assisted self-management led to successful outcomes and long term health outcomes.

“I finally realized that I could be an active participant in my own health, especially when I started to notice the positive changes. It was wonderful to see the results of my progress.” (Pamela’s Story Appendix 12)

Telehealth (phone service) offers potential for regional, remote and mobility restricted patients\(^ {16}\). Livestrong\(^ {17}\) and electronically available survivorship programs may offer advantages when used in conjunction with or as an alternative to face to face survivorship consultations to maximise time use.

**Objective 3. Access to allied health and community services**

**Outcomes achieved**

Survivorship assessment, and development of a care plan, allowed each individual participants requirement for allied health and community services to be identified. Overall, 47% of participants received direct referrals to allied health and community services, supporting Australian and International research that many survivors have unmet physical and psychosocial needs. The project team’s knowledge of allied health, community, and cancer specific health services within the region has been significantly developed, with greatly improved networks and referral pathways being established. A resource of cancer specific and general services available for survivors is being developed to be accessible by all parties. Allied health and community service professionals in the region have an increased knowledge and awareness of survivorship issues with additional education workshops to occur.

*Ryan’s Story: Early in 2011, Ryan was a 20 year-old with a passion for graphic design by day and drumming in a band by night. He felt soreness in his leg but brushed it off as too much drumming. After 9 months a diagnosis of osteolymphoma was revealed. Six months on Ryan had completed his cancer treatment but found it impossible to continue his studies or play in the band. He recognized his quality of life was significantly impacted on by his chronic fatigue and pain and twelve months later he was still living with the effects. A survivorship appointment and assessment led to his referral for rehabilitation within Barwon Community Health. Physiotherapy, hydrotherapy sessions and pain management helped him to regain the use of his leg, get his pain under control and his life back on track. Ryan was assisted to connect with a local GP who could support him to manage his health. Ryan says the survivorship project has been incredibly beneficial in helping him recover his physical fitness and to develop ways to cope. (Ryan’s Story Appendix 8)*

Following liaison by the survivorship service, Commonwealth Rehabilitation Service Australia has commenced vocational retraining services for 2 survivorship program participants.

**Enablers**

A range of health care providers have demonstrated their willingness to discuss and recognise the needs of survivors. Direct phone discussion from the survivorship nurse to health professionals prior to first referrals increased referral acceptance and enhanced the knowledge and development of service networks. Aligning survivorship needs with the similar needs of patients with other chronic illnesses\(^ {18}\) (e.g. cardiac, neurological and orthopaedic patients) was a very successful strategy to increase knowledge and acceptance of survivors of cancer as requiring allied health and community service interventions.

**Challenges**

A large numbers of cancer patients receive treatment on an outpatient basis, which is not well supported by referral to allied health services (at Barwon Health). A number of factors including the medical focus of treatment and the perception that Allied Health is not available may contribute to this. Patients who have
completed treatment and attend the Cancer Service for follow up review appear to have even less access to allied health services. Hamilton however reported greater availability to Allied Health practitioners.

Perceptions and the use of the term ‘multidisciplinary care’ vary considerably depending on the focus and training of the user and can cause considerable misunderstandings.

**Key learnings**

Prehabilitation (maximising health prior to treatment), rehabilitation & physical reconditioning are currently much underutilised in cancer management, but are extremely relevant for cancer survivors, and result in psychological and other health benefits

> "The exercise program really was a life saver. I have noticed a huge difference in the way I feel both physically and emotionally. I look and feel better and stronger, which has given me more confidence.‘

*(Cancer Survivor)*

Referral to rehabilitation community health and allied health services appear considerably lower for survivors of cancer than for other major disease groups. The number of regional, cancer trained, health professionals are limited, e.g. sexual health practitioners and speech pathologists for head and neck cancer survivors. However community services and Allied Health professionals appeared willing to accept patient referrals if supported by information and education. Placing cancer within the context and concepts of chronic disease promoted understanding and acceptance of referrals.

Specific cancer resources are centred in metropolitan areas and can be difficult for survivors to access, although some have telephone services. Support groups appear underutilised and are sometimes negatively perceived by cancer survivors. The removal of government support for the Dental Service impacted significantly on survivors.

> “Being a survivor is very expensive”. *(Head and neck cancer survivor Glenda’s Story Appendix 13)*.

**Sustainability**

Transitioning the holistic care of survivors to the community increases the likelihood of survivorship needs being met and future concerns being catered for as they arise. Increasing access to, and building on existing services within the community appears more sustainable and achievable in the short term, rather than seeking funding for the development of ‘cancer survivor’ specific services. Inclusion of cancer into Allied Health priority and intake systems will increase access, e.g. including lung cancer survivors on the eligibility list for Chronic Obstructive Pulmonary Disease (COPD) programs. Continued professional development activities will be required.

A physiotherapy provider in Colac has commenced a reconditioning and exercise group for cancer survivors based closely on a similar program for cardiac patients. Services can often be gained more quickly through private services and access to GPCDMPs. Continued identification of regional resources will create more extensive and established networks accessible to survivors.
Objective 4. Coordinated pathways of care between Cancer Services, Primary Care and Allied Health providers.

Outcomes achieved
Pathways of survivorship care from conclusion of treatment onwards, which promote GP engagement and transition of survivorship care from specialist to GP, were developed. As part of the NLSC nurse GPs were engaged in a phone discussion with the survivorship nurse (60% success rate was achieved).

The GPs of all participants received the individual Survivorship Care Plan plus a corresponding single page tumour-specific surveillance schedule that had been developed in consultation with oncologists and interest GPs. The tumour specific surveillance schedules were developed for each of the eight tumour streams and perceived as useful in the ongoing care of patients by 98% of the 50 GPs returning feedback forms. Survivorship care was successfully aligned with frameworks utilised regularly in primary care (e.g. chronic and preventative health care) and GPs demonstrated considerable interest in sharing or continuing survivorship care. A small number of survivors participating in the Nurse Led Survivorship Clinic (so within 2 years of treatment) were recommended by their cancer specialist as suitable for transition to GP care. General agreement that the survivorship service can take a key role in transitioning survivors between cancer specialists and GP increased as project acceptance developed.

The project identified that key partners accept that all versions of shared care should involve communication of patient information and increased knowledge and engagement of GPs in surveillance, recurrence and general health care screening. Variation arises from whether the GP is invited to complete some or all of the tests, examinations and scans traditionally addressed by the cancer specialist or asked to complete them at an earlier survivorship stage. ‘Shared cancer care’ would seem to be a term that helps distinguish this type of request and ‘alternating review of cancer care’ is another.

Cancer specialists showed considerable interest in transitioning patients greater than 2 years (and often up to 7 years or more) since completion of treatment to GP care (either ‘shared cancer care’ or discharged). A bonus aspect of the project utilised the survivorship pathways and documents to support 34 survivors (Haematology and Breast) more than 2 years post treatment (and not eligible for the NLSC) to shared or discharge GP care. This trial raises significant opportunities for further development with flow on effects reducing service delivery costs.

Enablers
GPs contacted by the Survivorship Nurses generally assumed and accepted their role in the ongoing care of patients after treatment, and showed a willingness to discuss patient care. GPs are often familiar with all
aspects of a person’s health and may manage the health and wellbeing of family members/carer. A person’s confidence in their GP’s ability to manage their ongoing care and knowledge that the GP had received survivorship documents from the SNLC was observed to influence patients’ acceptance of, or request that their GP provide follow up care.

GP preferences regarding resources and documents had previously been identified. The involvement of GP Practice Nurses in the development of chronic care plans and follow up of patients was identified as a major contributor to care coordination and service transition. Co-location and the close relationship between the GP practice and Hamilton Hospital was a significant enabler in developing coordinated care pathways. BML offered significant opportunities to access GPs and practice nurse groups, and for the project to align with related BML projects e.g. cdmNet, Health Pathways and the Allied Health project worker.

Challenges
Long held assumptions, perceptions and attitudes between specialists and GPs can interfere with the development and implementation of coordinated pathways of survivorship care.

GPs are generally time poor and reaching them on the phone often requires multiple calls. Survivors who do not use a regular GP practice, see a number of GPs at the one practice, attend bulk billing practices or fail to notify the centre of changes of GP all create challenges when developing coordinated care pathways.

Issues of trust and communication impact on willingness of both parties to ‘share cancer care’. Specialists indicated concern that not all GPs may have the required skills and knowledge to complete surveillance and cancer related follow up. The willingness of GP practices to follow up patients who fail to attend GP appointments for cancer care (treatment side effects can include memory loss) raised cancer specialist concerns that patients may “fall between the gaps” and re-present with more advanced cancer at a later date. Tumour streams vary in follow-up requirements and a comprehensive ‘one size fits all’ cancer tumour streams follow-up guideline could not be presented on a single page as preferred by GPs.

Gaining acceptance of new initiatives is challenging when tumour teams are relatively small, lack time and have other higher priorities. Loss of ‘cancer specialist champions’ (e.g. relocation) can impact hugely on project development. Confusion and misunderstandings caused by comprehension of the generic term ‘shared care’ can create a considerable challenge when working across health service contexts.

Key learnings
There is general agreement from cancer specialists that GPs could play an earlier and increased role in ‘cancer care’ of survivors who have no ongoing major concerns. GPs generally agree that they have a role in survivorship care and prefer single page documents for quick review, although the longer survivorship care plans were appreciated by GPs and Practice Nurses completing GPCDMPs. GPs recommend that their ‘involvement at all phases from diagnosis and through treatment can improve the survivorship experience’.

The term ‘shared care’, should be used in a general context only, with misunderstandings minimised if a brief explanation is added.

Initially cancer specialists were reluctant to design fixed guidelines for survivorship care e.g. 1-2 years, 3-5 years, >5 years but this is anticipated to change as the program grows in professional recognition. Specialists did however show considerable interest in an approach that allowed for individually tailored shared care arrangements as determined by them and communicated with the individual GP. This approach was piloted and involved; the specialist discussing shared cancer care with the survivor and gaining their agreement; inviting the GP to share cancer care following a program outlined by the specialist’s letter (e.g. regularity of review required, tests and examinations recommended); the survivorship service sending the
GP a short project introduction letter and a request to acknowledge agreement to share care (Appendix 14) and a copy of the appropriate surveillance schedule with a rapid re-referral phone number.

Factors impacting on the likelihood of sharing cancer care were identified as the time since treatment; absence of any major post treatment symptoms and concerns; specialist concern for high clinic numbers and need to release time for new patients; an existing relationship between GP clinic and the specialist e.g. Hamilton GP Practice; specialist awareness that the GP has agreed to share care and has received survivorship documents; the GP was known to have extra expertise or have previous involvement with the cancer centre; the patient has other significant illnesses being managed by the GP/specialist e.g. rheumatoid arthritis; survivors are required to travel long distances to see a specialist e.g. rural and remote locations and survivors request follow up with their GP, to avoid the distress of returning to the treatment centre.

**Sustainability strategies**

Increased engagement of GPs in survivorship care promotes patient, GP and cancer specialist confidence that long term survivor follow up will occur (e.g. 10, 20, 30 years later). Greater clarity regarding professional roles, responsibilities and medico-legal requirements will produce more acceptance and confidence regarding patient outcomes.

Greater engagement of practice nurse roles in chronic care management of patients has the potential to strengthen transition pathways and continue care. Assisting in the design of a GPCDMP for survivors, aligned with survivorship care plans will aid information transfer between service providers.

“This is exactly what needs to be included in the Chronic Disease Management Plans.” (Practice nurse).

Continued development of electronic communication pathways between specialists and PCPs is vital to improve sustainability. Administrative support until further electronic capability develops will maximise Survivorship Clinic productivity.

Utilising Medicare Local GP and practice nurse newsletters, as opposed to the development of a separate community of practice for survivorship (as suggested in the initial proposal) maximised existing communication strategies. Continued engagement with Medicare Local projects and the BML GP advisory board offers important opportunities to strengthen survivorship services. The opportunity also exists to utilise Telelink services for patients who have compromised mobility or live in remote area and GP (MBS supported) phone involvement in survivorship care planning.
Objective 5. A stratified risk assessment tool to guide selection of the appropriate level of survivorship care and follow up for each patient.

Risk equation - prescribes follow up care
The following conceptual model of individual risk has been developed from the current evidence base.\textsuperscript{21,22}

\[
\text{Risk of cancer recurrence} + \text{Risk of late effects} + \text{Risk of chronic disease} + \text{Holistic needs} + \text{Ability to self manage} + \text{Level of health literacy} = \text{Individual RISK} + \text{Prescribes follow up care} + \text{Geographic location, Individual preferences}
\]

Intended outcomes
Intended outcomes were to develop a written tool which could stratify levels of patient risk; align levels of risk with established follow up care guidelines; inform decision making including patients’ suitability for shared care with their GPs and relate to a range of tumour streams.

Enablers
A Haematology ‘champion’ interested in providing best patient care and in addressing the pressing issue of overcrowded haematology clinics was the major enabler.

Challenges
Whilst the topic of risk assessment is outlined in national and international publications few tools are accessible to inform this work. It became apparent that a ‘one size fits all cancers’ risk assessment tool would either too generic to be useful or extremely complex to develop and utilise. The need to access all tumour stream teams and the lack of an available senior clinician to lead the initiative were significant challenges. The perceived concern that a risk assessment tool may impact on patient care pathways and decision making may have also created resistance, particularly initially.

Key learnings
Medical and non-medical factors likely to contribute to patient risk were identified (see model above). Cancer specialists continue to assess risk of cancer recurrence and late effects of treatment but are willing to share ‘cancer care’ with GPs on an individual patient basis particularly where patients are more than 2 years post completion of treatment.

While completing the survivorship clinic assessment and care plan (for patients within 2 years of completion of treatment) the Survivorship Nurse completed risk assessment of holistic needs and chronic illness and transitioned this to the patients GP.

The development of a risk assessment tool specific to each tumour stream (following a similar template) is considered achievable and requires a high level of specialist collaboration, the presence of working guidelines for follow up care incorporating all treatment regimens, and a pilot with one cancer team that can be broadened out to all tumour streams.

The generalised assumption was observed, ‘that the cancer centre is best equipped to respond to patients at high risk and GPs best to respond to patients with low to medium levels of risk’ and the project team felt this warrants challenging and further investigation.
Objective 6. Implementation of a multidisciplinary clinic that provides long term follow up for high risk survivors of cancer.

Intended outcomes
The intended outcome was to design and implement a multidisciplinary clinic that provided long term care for high risk survivors.

Challenges
The implementation of a separate clinic for high risk survivors from a range of tumour streams (as outlined in the initial proposal) lacked agreement or support from existing cancer specialists and leaders. Specialists reported that patients remaining within current streams and areas of expertise would provide best follow up care. A clinical lead and survivorship specialist working to spearhead the initiative across a range of cancer types and on ongoing basis was required but not available.

Discussion identified that each cancer team would recommend different specialists be involved in the multidisciplinary team, e.g. a dentist for head and neck cancer survivors or fertility specialist for transplant survivors, making resource coordination and funding challenging and potentially unsustainable. The range of nonmedical and holistic needs of high risk survivors were generally less well recognised by cancer specialists. A multidisciplinary approach required Allied Health staff that were not included in project funding.

A new clinic structure also raised the requirement for further team meetings and communication strategies outside existing forums. The roles of professionals required clarification, including that of the GP and/or physician initially suggested. The proposed use of the MBS funding model for a GP position was considered to offer insufficient remuneration to attract a GP, and the engagement of the GP of each survivor in ongoing care was considered a preferred model. Concern was raised that high risk patients may not be able to benefit from detailed information from a range of providers on the same day, although reduced traveling would be appreciated.

Key Learnings
Provision of care is clustered within tumour streams and to unpack this is not feasible, particularly in regional centres. Encouraging all clinicians to become ‘survivorship focused’ and aware may offer greater sustainability. An alternative model to the high risk multidisciplinary clinic emerged with one team grouping higher risk patients on an existing clinic day. Any multidisciplinary services available in the future may coincide services with these clinics and result in a more feasible and sustainable approach. The lack of Allied Health and rehabilitation services for high needs and high risk survivors requires addressing.

Revisiting the benefits of a high risk clinic as survivorship gains greater acceptance within the cancer service trajectory is recommended.
Evaluation Results
The evaluation framework developed by Deakin University Faculty of Health and the project team comprised both qualitative (interviews) and quantitative components (surveys and questionnaires) (Evaluation Flow Chart Appendix 15). Participants completed written questionnaires prior to, one week after and then again 3 months after attending the nurse led service. Questionnaires included The Health Literacy Questionnaire (HLQ), Assessment of Quality of Life – 8D (AQoL 8D), Health Education Impact Questionnaire (heiQ) and questionnaires designed to collect information regarding resource use, economic cost, patient satisfaction and professional acceptance and feedback.

Recruitment: Overall, 129 people were approached to be involved in the survivorship clinic and evaluation, seven patients received services but were ineligible due to a lack of English skills to complete questionnaires; some did not complete the questionnaires or failed to attend appointments and 17 declined to be involved, leaving 99 (81%) participants. Reasons for non-participation included “didn’t want to be reminded of the cancer experience”, “I’m doing OK”, “too busy” or “doing fine and have gone back to work”.

Sample Characteristics: A total of 84 participants (85%) completed the one week post SNLC follow up evaluation questionnaire. Overall, 90% of participants reported the two consultations with the survivorship nurse was either ‘quite’ or ‘very’ helpful; 77% reported contact with the survivorship nurse would help them raise issues with their health provider 82% reported the survivorship care plan was helpful; 51% of participants reported they received referrals from the survivorship nurse to additional services during their consultation, including referrals to a nutritionist, hospital based or private or community based social worker, GP, dentist, cancer support group, sexual health counsellor, physiotherapist or exercise psychologist and podiatry. A total of 89 referrals were made during the program and 42 referrals were followed up by participants within three months of receiving these referrals, currently 17 referrals are still in the process of being followed up.

![Participants reported the survivorship nurse helped them:](image)

Figure 1. Participants reported the impact of the survivorship clinic on psychosocial outcomes one week after consultation at the survivorship clinic, and again three months later.
Three-month follow-up: A total of 74 (75%) participants completed and returned the three-month evaluation questionnaire, of which two-thirds (n=48) reported they continued to use their survivorship care plans (SCPs) over the preceding three month period.

Participants’ comments at 3 months include:

“It was a very informative appointment to help proceed with the next stage of my life.” (Female, 80 yrs)

“Made me aware of the need to watch for any symptoms to discuss them with doctors.” (Female, 69 yrs)

“Keep up the good work as it is hard to have someone with time to listen to your concerns about your cancer & the results of its side effects.” (Male, 71 yrs)

“Great to know that it is there and be reminded of other readily available resources. Unless you are in the system you don’t know what is actually available.” (Female, 62 yrs)

“I do think it is a wonderful idea. A patient is not just left overwhelmed at the end of treatment, possibly feeling alone and/or confused. I hope it can stay for others in future.” (Female, 49 yrs)

Health Education Impact Questionnaire (heiQ): The Health Education Impact Questionnaire (heiQ) comprises 40 questions divided into eight distinct domains/themes. All project participants (n=99) were asked to complete the heiQ at all three time points Time 1(T1): initial consent and appointment; Time 2 (T2): within one week of the 2nd consultation at the NLSC and Time 3 (T3): three months after attending the NLSC. The heiQ data was available from 98 patients at T1, 84 patients at T2 and 74 patients at T3.

A repeated measures Analysis of Variance (ANOVA) was conducted with no significant differences observed between the mean scores across time for all the eight heiQ domains. However, the results showed a general trend of an overall increase in mean scores from T1 to T2 and/or T3 for one domain, i.e. participants being able to manage the challenges of the cancer experience and of having a sense of control.

Health Literacy Questionnaire: The Health Literacy Questionnaire (HLQ) comprises 44 questions that are divided into nine distinct domains/themes. All participants (n=98) were asked to complete the HLQ at the same three time points same as the heiQ above. HLQ data were available for 98 patients at time point T1, 84 participants at T2 and 74 participants at T3.

A repeated measures Analysis of Variance (ANOVA) was conducted and a significant change in four out of the nine domains was demonstrated. There was a significant change (p<0.05) observed in Healthcare Provider Support (HPS), $F(2, 118) = 3.79, p =0.025$; Having Sufficient Information (HSI), $F(2, 118) = 6.66, p =0.002$; Critical Appraisal (CA), $F(2, 118) = 7.48, p = 0.001$, and Navigating the Healthcare System (NHS), $F(2, 118) = 3.27, p =0.041$ domains, on the HLQ. These were further analysed and a significant increase in HPS, his, CA, and NHS was observed from Time 1 (baseline) to Time 2(one week post-Intervention) but not between Time 2 and Time 3 (three month follow-up). In addition, a general trend of an overall increase in mean scores from T1 to T2 and/or T3 on the other domains was observed but did not reach significance. Overall this change suggested a significant overall improvement in patients seeking and understanding health related information and overall improved health literacy levels.

Economic assessment

The economic assessment of the project consisted of a cost-outcome analysis, to estimate the costs of the intervention related resources, compared to patient outcomes. Incremental cost-effectiveness ratio(ICER) are not reported as a comparator to the intervention is not available in the current assessment.
Health Outcomes
Health outcomes were assessed by the Assessment of Quality of Life – 8 Dimension (AQoL-8D) questionnaire. The AQoL-8D is a 35 items instrument with 8 dimensions (independent living, pain, senses, relationships, mental health, coping, happiness and self-worth) which may also be combined into two “super dimensions” for mental health and physical health. Findings from the AQoL-8D questionnaire score show that the project participants have a lower level of utility at baseline compared to population norms (0.68 versus 0.8(pop norm)), which means the quality of life of these cancer survivors are worse than the general population. There appears to be a slight improvement in the quality of life utility score from 0.68 to 0.70 by the time of the 3 month follow-up. Inspection of the physical and mental health super-dimensions of the scale indicates small improvements appear in mental health (from 0.40 to 0.43) and in physical health (from 0.62 to 0.64). All the changes in AQoL-8D and super-dimensions from baseline to follow-up are not statistically significant; however the observed changes are in the expected direction.

Costs
Costs were assessed in two components, i.e. the cost of the Nurse Led Survivorship Clinic (NLSC) intervention and the cost of the healthcare and community resources used by participants after referral by the Survivorship Nurse. Costs are reported in total for all participating cancer survivors, per person who received referral or attended health service and per referral appointment.

The cost of the NLSC was estimated to be approximately $145,000 per annum. This annual cost included $131,000 for personnel, $3,000 for facility and capital and $11,000 for consumables (e.g. telephone, print, stationery, computers and software).

Patient referrals made by the Survivorship Nurses to healthcare services and community resources (e.g., psychologists, physiotherapists, podiatrists etc.) were collected by the evaluation questionnaires at the time of post Survivorship Nurse Clinic appointment and three month follow-up. Forty seven participants received 100 referrals to health care services and community resources which represented a total cost of $5,110. Of this total, $3,674 was incurred by the public sector and $1,436 was paid by the participants as out-of-pocket expenses being the difference between the fee charged by private healthcare providers (e.g. private psychologist, dentist, dietician, physiotherapist etc.) and the amount of rebate the patients can claim from Medicare or private health insurance. Importantly, these costs only reflected referrals to be attended and did not include further follow-up services incurred as a result of these referrals. For each patient who received referral from the Survivorship Nurse at the time of post Survivorship Clinic, the average cost was $110 per person and $52 per referral appointment.

At the three month follow-up, total cost of healthcare resources used or to be used indicated by patients was $5,906, with $3,916 of this to be paid by the public sector and $1,990 paid for by the private sector as patients’ out-of-pocket expenses. For each patient who has attended the referral appointments at three month follow-up, the average cost was $219 per person and $66 per referral appointment.

The cost assessment demonstrates the NLSC not appear to incur many resources costs, with the main costs being attributed to survivorship nurse salaries. It is currently not known whether the NLSC has resulted in any cost-savings to the organisation or to the broader health sector; however, it is hoped that the next level of evaluation of this clinic will include a comparison group so that a full economic appraisal of the clinic is possible.

GPs: Stage 1. GPs were sent a letter when their patients completed the NLSC introducing the survivorship project and providing the Survivorship Care Plan (SCP) and single page GP Tumour Surveillance Guide. GPs were asked to feedback on the usefulness of the 2 documents provided. Fifty surveys were returned by GPs with 92% stating the Survivorship Care Plan was useful in the ongoing care of their patient, 96% reporting the Surveillance Guide was useful to the ongoing care of the patient and 98% indicating the format was useful.
“I think it is a good initiative and will improve patient care.”
“Looks excellent and well balanced – Thanks.”
‘Well set out. Easy to read. Excellent resource!”
“Thanks great tools to help follow up of this patient.”
“V. useful guide for GPs.”
“Great idea – cancer patients are often ‘forgotten’ after their treatments is concluded.”
“I think this is more than Excellent. Clear organised information for both Health Prof and patient.”
“Very clear guidelines and instructions, perfect effort.”

GPs: Stage 2 involved a survey to 79 GPs across the region, whose patients had completed and were involved in the evaluation of the NLSC. Forty-five out of 79 surveys were returned and of those GPs who had seen the cancer patient, 97.5% reported that they utilised GP Management care plans and team care plans in their practice; 89% indicated that the survivorship documents were useful in the development of chronic disease management care plans and/or team care arrangements; 52% reported they referred to the tumour specific surveillance schedule and of these, 89% believed the schedule provided appropriate information to assist long term care of this patients health and 68% indicated the SCP assisted in long-term care of the patient. GPs also indicated that the SCPs increased their patients’ confidence to discuss post-treatment health needs (67%) and motivated their patients to take actions to address their health needs (83%).

Practice Nurses completing an evaluation of an education workshop provided by the survivorship team indicated a high level of interest in addressing survivorship issues within their work roles, and in application of the survivorship care plans to GP Chronic Disease Management Plans.

Cancer Specialists: Twelve of the 20 cancer specialists contacted (5 Radiation Oncologists, 4 Medical Oncologists, 2 Haematologists and 1 Other Cancer Specialist) completed the specialist evaluation questionnaire. Each of the specialists rated a ‘moderate to high’ level of success in their belief that the SNLC program achieved its aims; 75% of respondents discussed the survivorship program with their patients; 92% indicated that they rated the success rate of the program to be moderate to ‘very high’ to enhance continuity of care between cancer specialists and GPs and 92% rated a ‘high to very high’ success rate of the program in providing a patient centred approach; 55% rated a ‘moderate to a very high’ success rate in establishing a sustainable model of care; and 70% believed that the Cancer Survivorship Project had improved post-treatment care for their patients. Cancer specialist comments included:

“The survivorship team has more time and knowledge to address survivorship concerns and provide advice and guidance about life after cancer treatment.”
“A more comprehensive approach is provided by the team and I recommend that the service could be improved through consolidating the practice into routine patient care at Andrew Love Cancer Centre.”
“I have a special interest in breast patients and their post treatment care. I recognize that they receive very intensive treatment and then get abandoned.”
“Patients discuss physical and psychological problems with the survivorship service, which may have been overlooked or not said to a doctor.”
“The oncologist workload has not been impacted on, but patients have benefited by receiving greater service.”
“Patients are very happy with the program.”
“Survivorship team worked very well at the Andrew Love Cancer Centre clinics.” (Barwon Health Geelong)

Health Professional Evaluations: Fourteen evaluation surveys were returned from cancer nurses, specialists nurses, radiation therapists and Allied Health professionals who had instigated patient referrals to the NLSC. Overall this group reported a high level of satisfaction and acceptance for the survivorship
service. The professionals rated either a ‘high’ or ‘very high’ (93) level of success of the program to develop a model of care that responds to the needs of survivors. Eighty six of these professionals also rated a ‘very high’ success rate of the program to provide written Survivorship Care Plans. Overall, 86% rated ‘high’ to ‘very high’ success rate of the program to enhance continuity of care between cancer specialists and GPs and all the professionals again rated a ‘high to very high’ success rate of the program in providing a patient centred approach. Seventy-eight percent of professionals rated a ‘high to a very high’ success rate in establishing a sustainable model of care.

Health Professionals from this group commented that:

“Patients have stated they have obtained direction and had an easier transition back to ‘normal’ with the added support.” (Cancer Nurse Specialist)

“Survivorship provides a deviation from a service that is purely concerned with the medical realm post-disease realm, and includes prevention of mental health problems (i.e. chronic disease) through early identification of problems.” (Clinical Psychologist)

“Survivors are linked with services which would normally have been missed.” (Occupational Therapist)

“Would like to see this expand to other sites.” (Radiation Therapist)

**Allied Health evaluations:** Eight Allied Health professionals who received referrals from the NLSC, have returned surveys and all reported that survivorship service provides a more comprehensive focus addressing all aspects of patient than traditional medical review. All Allied Health professionals also indicated that the referral received was appropriate for their service and that they were able to meet the needs of referred patients. More than half of these professionals indicated that the SCP helped in meeting their patient’s needs and also motivated their patients to take actions addressing their health needs. Almost 60% of the respondents indicated that the survivorship program improved post treatment outcomes for the patients.

Overall, 47% of participants of the project received referrals to a wide range of allied health and community services, and discussion with these services indicates that many survivorship needs can be met by referral to existing health services if liaison and information is provided. Waiting time for some existing Barwon Health allied health and community referrals can be long, whilst this may not be experienced at other sites. As referrals have been widespread, any resulting impact on the services wait lists does not appear significant and none of the feedback from these professionals indicates any workplace related issues.

The additional pilot supporting the Haematology and Breast tumour steams to share ‘cancer care’ of medium and longer term survivors (over 2 years since completion of treatment) who were considered by the specialists to be at low to medium risk was not formally evaluated. The care of 34 survivors of cancer from 2 to 14 years post completion of treatment (and therefore not eligible for the survivorship nurse led service) was assisted to transition to ‘shared cancer care’ or full discharge of care to the GP. Specialists reported an interest in further developing this aspect of the project with the view to reducing overloaded clinics and ensuring new and complex patients receive timely care. Clinicians reported not having the time to develop policies, procedures, agreements and documentation regarding this pilot and were interested to review and input on those developed by the survivorship team. GPs generally reported a willingness to share cancer care and all returned signed acknowledgement of the specialist’s invitation. (Some reminders and follow up of change of GP was required).

**Recommendations from the evaluation:**

This demonstration project provides important information on the feasibility and acceptability of introducing a Nurse Led Survivorship Clinic following completion of active treatment. The evaluation demonstrated improved health literacy and a trend towards self-empowerment among participants. The
project also provides valuable insights for planning of a larger randomised controlled trial (RCT), involving a comparison group who receives usual care, which is required to truly demonstrate the effectiveness and cost effectiveness of this new model of care. In the short term, continuation of the survivorship clinic will enable further patients to be recruited and followed up, which will contribute significantly to evaluation and economic data required for the development of a RCT proposal to the National Health and Medical Research Council (NHMRC) in 2015.

**Issues and challenges with the evaluation.** Challenges experienced with project evaluation were similar to other healthcare research including recruitment of patients into evaluation studies and the need to prompt return of questionnaires following the 2nd clinic and three months later. A pleasing result was the considerable number of GP responses returned (GP Stage 1 Evaluation) after GPs were introduced to the project and asked to comment on the content and format of the survivorship documents.

**Sustainability considerations**
Sustainability considerations have been included in the outline of each objective outlined earlier in the report and summarised in Appendix 16. All aspects of the SNLC trialled during the pilot project are potentially sustainable. Implementation of a Multidisciplinary High Risk Survivorship Clinic was not pursued past the planning stages due to concerns about sustainability after project completion. Issues contributing to continued sustainability of the project include advancements in technology, continued presence of cancer specialist champions and tumour team support, culture change allowing acceptance of the survivorship phase within the cancer service trajectory, organisational support, engagement with GPs and Barwon Medicare Local projects and ongoing funding for Survivorship Nurses and Project Manager (during continued project development).

**Potential scope for extension/spread of survivorship care**
The project demonstrated that a nurse led survivorship service can successfully translate across sites as a central hub with satellite and outreach clinics, with potential to spread and be applied to other regions. All three sites (Geelong, Hamilton and Colac) utilised similar project design, procedures and documents. The advantages of site specific placement across the region, while maintaining a central coordination hub, include shared knowledge and learning, efficiencies and consistencies whilst utilising local knowledge, utilising existing partnerships with GP, allied health and community services and increased access locally for participants. Flexibility to meet the individual strengths and needs of a community and region are recommended when establishing survivorship services.

The project has clearly demonstrated that a Nurse Led Survivorship Clinic can be successfully delivered to a range tumour stream (8 to date with documents also prepared for the large prostate cancer group) and has potential application for survivors of all cancer types. Extending eligibility of the program to patients living with cancer and receiving ongoing long term treatment (e.g. myeloma) is recommended. Within the Barwon and South Western Cancer Region there is also opportunity to incorporate the other Victorian Department of Health Survivorship Projects e.g. the Melanoma Shared Care Project and Royal Women’s Hospital Breast Cancer Survivorship Programs.

**Key steps recommended in adopting this survivorship model**
For key steps recommended in adopting this model please see Appendix 17.
Next steps for the project – next 2 years
We aim to continue offering a survivorship service extending on the outcomes of the pilot project.

Objectives for the next 2 years
1. Ensure ongoing organisational funding. Ensure ongoing organisational funding including preparation for ABF funding release in 2014/15.

2. Embed the Nurse Led Survivorship Service. Embed the Nurse Led Survivorship Service into clinical practice, with a focus on streamlining services and increasing efficiencies, building on IT capabilities to increase capacity and sustainability of services (e.g. greater application of the ARIA upgrades and use of additional IT programs and data bases); trialling Cancer Services to GP IT platforms or identifying other potential platforms (e.g. cdmNet), continuing engagement and education of PCPs and promoting access to allied health services and trialling Telehealth services. Significant opportunity exists to build on related organisational projects e.g. development of treatment and follow-up guidelines, mapping of cancer trajectories and the development of the new Cancer Supportive Care/Wellness Centre. An administrative review and transition of tasks to Cancer Centre business operations is proposed. A major continuing project focus is to reduce risk, and increase sustainability and knowledge/skill base of survivorship services.

3. Expand Survivorship Services. Survivorship services and eligibility will be expanded to include other cancer tumour streams including the large population of prostate survivors as well as patients living long term with the impacts of cancer and cancer treatments (e.g. myeloma).

4. Provide consultancy services. Considerable opportunity exists to share the projects learnings and resources with survivorship projects and initiatives in other regions, as well as with other clinical teams working with patients who would benefit from survivorship services (eg receive surgery only). Investigating and supporting the implementation of other VCSP projects (Melanoma, Colorectal and Breast Projects) within Barwon Health and Barwon South Western Region and investigating the capacity and appropriateness of Cancer Link Nurses taking on survivorship roles in the rural centres offer 2 further consultancy roles.

5. Development of shared care and transition pathways from Cancer Centre to Primary Care. Further trial and audit of the transition pathways for survivors of cancer to ‘shared cancer care’ or discharge to GPs presents considerable patient, service and economic outcomes, particularly where patients greater than 2 years post completion of treatment are included.

Overview of project impact
Impact and value to key stakeholders:
Survivors. This new model of care has the potential to provide improvements in the delivery of services to survivors of cancer, by improving health literacy and patient empowerment, as well as enhanced satisfaction with health services following treatment for cancer. Results indicate the service carries significant potential to meet the ongoing psychosocial needs of survivors of cancer over time, by improving patients’ confidence in their ability to navigate the health care system. Just fewer than 50% of participants of the survivorship service received referrals for allied health and community services and feedback indicates that many survivorship needs can be potentially met by referral to existing health services if liaison and information is provided.

Assessment of Quality of Life scale indicated small improvements appeared in mental and in physical health. The Survivorship Service offered considerable opportunities and outcomes for health improvement and cost savings both for the individual patients and at the organisational level. The evaluation of cost benefits to the survivors from improvements in health from preventing or reducing effects of treatment...
and chronic illness such as cardiovascular hypertension, distress and depression and allowing return to work and daily life was outside the scope of this project.

The outcomes of a bonus trial aimed at ‘sharing cancer care’ with GPs for survivors who are greater than 2 years post treatment, was not formally assessed. However this offers significant opportunity to clarify service provider roles; improve communication and transition pathways between service providers; and offers considerable potential cost savings and freeing of resources and funds to be directed towards new and complex patients.

**Cancer Specialists.** Each of the specialists rated moderate to high the success in their belief that the Survivorship clinic achieved its aims; 75% of respondents discussed the survivorship clinic with their patients; 92% indicated that they rated the success rate of the program to be from moderate to very high of enhancing continuity of care between cancer specialists and the GPs; 90% rated high to very high the success rate of the program in providing a patient centred approach.

**GPs.** GPs highly rated the survivorship documents in assisting ongoing care of the patient; they indicated that the survivorship documents were useful in development of chronic disease management care plans and/or team care arrangements, and 52% had referred to the tumour specific surveillance schedule. GP Practice Nurses were identified as valuable members of the survivorship team.

**Key Learnings of the project include the following:**

**Cancer Survivors.** The nurse led survivorship model has the potential to extend to all cancer types and to patients living on long term treatment regimens. Provision of information at a ‘teachable moment’ when participants are considering ‘the rest of life health’ is unmeasured but may result in significant longer-term health benefits and cost savings. Prehabilitation, rehabilitation & physical reconditioning are relevant for cancer survivors and result in psychological and other health benefits but are much underutilised at present. Existing referral to health professionals and rehabilitation services appears lower than for other major diseases and needs further investigation and communication within the relevant service contexts. The needs of survivors of cancer vary and an individualised service is ideal, however the potential demand for services may require a modified sustainable approach.

**Cancer Services.** Cancer services currently address cancer as an acute illness however cancer has a lifelong impact on both patients and carers and should be addressed as a chronic (longer term) condition. Opportunity exists to further examine and support the transition of survivors (particularly those 2 years or more since completion of treatment and with no ongoing difficulties to PCPs).

**The use of language.** A consistent observation relates to the large variation in utilisation of terminology including ‘clinic’, ‘shared care’ and ‘chronic care’. Brief elaboration to establish shared meaning and perception can assist and avoid potential misunderstandings and conflict.

**Shared cancer care and transition of survivorship care to Primary Care Providers.** Key partners accept that there is opportunity to further improve coordination, shared care and transition of survivorship between Cancer Services and PCPs. Clarification of medico-legal responsibilities may accelerate further progress and acceptance. Individually tailored shared care arrangements as determined by specialists and communicated with the GP have the potential to lead to the establishment of guidelines and risk assessment tools as the survivorship project grows in support and professional standing.

**Policy & systems level questions raised by this project include:**

Cancer Strategy and Development has clearly demonstrated its commitment to advancing survivorship care through their investment in pilot projects across within Victoria and also with its support of the Australian Cancer Survivorship Centre. Despite this there remains a lack of awareness and understanding of
survivorship at operational levels in Health Services. While there have been efforts to engage management staff locally in our region, this task would be made easier if supported by a State-wide policy document. There may be an opportunity to consider other points of leverage such as incorporating cancer survivorship requirements within current performance management and reporting structures already in place for Health Services.

There will be an ongoing cost of providing nurse-led survivorship intervention at Barwon Health and regional sites. Transitioning the cost from the project budget to the Health Services’ operational budget is likely to be problematic particularly in the absence of a policy context. The Activity Based Funding (ABF) Tier 2 Clinics appear to be providing opportunities for nurse-led clinics and the survivorship service is likely to meet the criteria under the 40.52 item. However the details of the ABF are still unclear, particularly around the potential for growth funding to provide new services.

Implementation of clinically based survivorship programs raises the importance of building a theoretical knowledge base and incorporating survivorship education and training into the medical, nursing and allied health tertiary curriculums.

Top Ten Tips
1. Identify and develop ‘survivorship champions’ as a key to ongoing success.
2. Listen to and identify the specific interests and motivations of key stakeholders to aid engagement.
3. Develop draft documents and frameworks for review by specialists and GPs to generate progress.
4. Regularly repeat messages about survivorship, as it is not everyone else’s focus (e.g. clinicians).
5. IT capabilities are improving (albeit very slowly) and offer sustainability benefits.
6. Align with other projects and services as a way of gaining sustainability and leverage.
7. Apply patient examples when developing survivorship guidelines, documents and processes to highlight issues and actual outcomes that may not arise when the project design is discussed in general.
8. Ensure data is collected to extend the evidence base for the project and survivorship.
9. Engage consumers in all stages of project development.
10. Maintaining a focus on ‘outcomes for cancer survivors’ can assist when differences of opinion arise.

Project Recommendations
Project outcomes demonstrate that SNLCs are valued by survivors, cancer specialists and staff, and Primary Care Providers. Extending the eligibility to further tumour steams is strongly recommended. A health professional needs to take leadership in survivorship, and nurse-led programs appear to do this well.

State-wide policy development, impacting at organisational levels, will aid survivorship service development. Funding to expand the project will increase survivorship skills and knowledge base, allow for further consultation, allow for further data collection, and potentially lead to significant cost savings.

A number of current and new health projects in the region offer significant opportunities to leverage survivorship care and greatly improve project and participant outcomes. In regional areas, establishing SNLCs based at the major centres, providing outreach services to smaller rural centres, appears a successful.

Improved IT capabilities (e.g. sharing of information between cancer centres and GPs) offer sustainability benefits. Carers’ needs are not well identified or met and should be investigated and developed, building on work already completed within other major illness groups (e.g. Carers Victoria 23).

In the short term, continuation of the survivorship clinic will enable further patients to be recruited and followed up, which will contribute significantly to evaluation and economic data required for the development of a RCT proposal to the National Health and Medical Research Council (NHMRC) in 2015.
List of appendices- Barwon South Western Survivorship Project

Appendix 1. Project Board Members

Appendix 2. Organisational structure

Appendix 3. Survivorship Care Plan- non Hodgkin Lymphoma

Appendix 4. GP Tumour specific surveillance guideline- non-Hodgkin Lymphoma

Appendix 5. Resources developed

Appendix 6. Communication strategy

Appendix 7. Survivorship Article- BSWRICS Annual Report 2013


Appendix 9. Workforce training and education

Appendix 10. General Health Assessment

Appendix 11. NCCN Distress Thermometer

Appendix 12. Pamela’s story

Appendix 13. Glenda’s story

Appendix 14. GP letter - Project introduction and agreement to share cancer care

Appendix 15. Evaluation structure

Appendix 16. Summary of sustainability strategies

Appendix 17. Key Steps to implement this model

Appendix 18. Expenditure summary

Appendix 19. Authorship

Appendix 20. Certifications

Appendix 21. Acknowledgments

Appendix 22. Two paragraph lay summary suitable for general public / press release

Appendix 23. One page lay summary suitable for general public
<table>
<thead>
<tr>
<th>Members</th>
<th>Position and Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professor David Ashley</td>
<td>Director of Cancer Services Barwon Health, BSWRICS Director</td>
</tr>
<tr>
<td>Associate Professor Michael Jefford</td>
<td>Director Australian Cancer Survivorship Centre</td>
</tr>
<tr>
<td>Kate Schofield</td>
<td>Project Manager, Barwon South Western Regional Integrated Cancer Service. (BSWRICS)</td>
</tr>
<tr>
<td>Donna Lever</td>
<td>Survivorship Nurse Barwon Health and BSWRICS</td>
</tr>
<tr>
<td>Jane Sharp</td>
<td>Survivorship Nurse, Western District Health Service (WDHS)</td>
</tr>
<tr>
<td>Margaret Dempsey</td>
<td>Project Officer, Barwon Medicare Local (BML)</td>
</tr>
<tr>
<td>Roger Northam</td>
<td>Consumer Representative</td>
</tr>
<tr>
<td>Spiri Galetakis</td>
<td>Program Manager, Victorian Integrated Cancer Services, Cancer Strategy and Development, Department of Health</td>
</tr>
<tr>
<td>Dr Michael Homewood</td>
<td>General Practitioner, Lara Medical Centre</td>
</tr>
<tr>
<td>Professor Trish Livingston</td>
<td>Associate Dean – Research, Faculty of Health, Deakin University</td>
</tr>
<tr>
<td>Professor Richard Osborne</td>
<td>Deakin University, Chair in Public Health.</td>
</tr>
<tr>
<td>Dr Rhonda Brown</td>
<td>Deakin University</td>
</tr>
<tr>
<td>Associate Professor Cathy Mihalopoulos</td>
<td>Health Economics, Deakin University</td>
</tr>
<tr>
<td>Rosie Rowe</td>
<td>Director Primary and Preventative Health, Western District Health Service</td>
</tr>
<tr>
<td>Anne Woollet</td>
<td>Manager of Research and Trials, Barwon Health Cancer Services</td>
</tr>
<tr>
<td>Kate Morrissy</td>
<td>Program Manager, BSWRICS</td>
</tr>
<tr>
<td>Dr Inger Olesen</td>
<td>Medical Oncologist, Barwon Health Cancer Services</td>
</tr>
<tr>
<td>Leanne Fagg</td>
<td>Consumer Representative</td>
</tr>
<tr>
<td>Marita Reed</td>
<td>Service Development Manager, BSWRICS</td>
</tr>
</tbody>
</table>
Appendix 2 Project Organisational Structure

**Project Board**

- **Project Lead**
  - Director of Cancer Services BH
  - BSWRICS Clinic Director

- **BSWRICS Governance Group**
- **BSWRICS Program Manager**
- **BSWRICS Survivorship Program Manager**
- **Survivorship Nurse Barwon Health**
- **Survivorship Nurse Western District Health Services**
- **Research Assistant**
- **Western District Health Services**
- **Deakin University - Research - Health Economics**
- **Barwon Medicare Local**
- **General Practitioner**
- **Australian Cancer Survivorship Centre**
- **Consumer representatives**
- **Barwon Health**
- **Great Southern Coast Medicare Local**

**Other Key Stakeholders**
- Barwon Medicare Local Project Workers
  - cdmNet
  - Health Pathways
  - Allied Health
- Barwon Health GP Liaison Team
- Barwon Medicare Local GP Advisory Group
- Allied Health
  - Western District Health Services
  - Barwon Health
  - Community Health
Appendix 3 Survivorship Care Plan - non Hodgkin Lymphoma

BARWON HEALTH CANCER SERVICES

Improving the health and well-being of survivors of cancer

Non Hodgkin Lymphoma Care Plan

<table>
<thead>
<tr>
<th>Diagnosis - with aim of cure</th>
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<tbody>
<tr>
<td>Events during treatment</td>
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<tr>
<td>Other medical conditions-</td>
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</table>

<table>
<thead>
<tr>
<th>Treatment given</th>
<th>Treating Specialist</th>
<th>Dates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chemotherapy:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiotherapy:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery:</td>
<td></td>
<td></td>
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<tr>
<td>Hormonal:</td>
<td></td>
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</tr>
</tbody>
</table>

**Important symptoms to watch for and to discuss with your doctor if they occur**

- Firm painless swollen lymph nodes
- Unintentional weight loss
- Night sweats
- Persistent loss of energy
- Generalised itching
- Recurrence of presenting signs & symptoms
- Worrying new symptoms – shortness of breath, pain, bloating, etc

**Recommended Follow-Up Plan**

<table>
<thead>
<tr>
<th>Recommended Follow-Up Plan</th>
<th>Type of review</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Regularity of review</strong></td>
<td></td>
</tr>
<tr>
<td>• Year 1 and 2, every 3 months</td>
<td>• Blood tests - FBC, U &amp; E including Serum LDH</td>
</tr>
<tr>
<td>• Year 3, every 4 months</td>
<td>• Examination – history of health and physical exam</td>
</tr>
<tr>
<td>• Years 4 and 5, every 6 months</td>
<td>• Scans only if necessary</td>
</tr>
<tr>
<td>• Year 6 and onwards, every year</td>
<td></td>
</tr>
</tbody>
</table>

**Possible effects of your treatment to discuss with your health team if they occur**

- Excessive tiredness, difficulty sleeping
- Altered interest or impaired sexual intimacy
- Tingling, numbness or pain in fingers and toes
- Shortness of breath, chest pain or heart racing
- Swelling of arms or legs
- Distress, anxiety, depression
- Possible impaired fertility
• Memory loss or confusion
• Education, employment and social difficulties
• Persistent pain including bone pain
• Dental concerns
• Weight changes
• Risk of new cancers later in life - look for new signs of bruising, bleeding

Patient Goals:

✓
✓

Recommendations from your assessment:

✓ Focus on maintaining good bone health long term – this includes 3 serves of calcium each day and regular weight bearing exercises. Discuss with your GP who will be your greatest resource
✓ Include regular exercise (30mins every day) into your daily routine. Consider what options might be of personal interest – gym programs, local walking groups, local exercise groups
✓ Current BMI ----- (Healthy range is between 20 and 25). Aim for a waist measurement of less than 80cms for women and 94 cms for men
✓ Aim to incorporate “Mindfulness” (relaxation & meditation) into your daily routine – start with ten minutes of relaxation twice a day. Use your relaxation CD or try some apps for use with a computer or smart phone – “Smiling Mind” or “Simply Being”. Refer to the information sheet in your folder
✓ Consider involvement in the Living Well After Cancer Program – the next session is ----
✓ Ensure you protect your skin with sun safe practices, especially the skin within a treatment area
✓ Increase your intake of “colourful” vegetables to at least 5 serves(or 5x½ cups) each day
✓ Visit the dentist every 6 months, starting 12 months after treatment has been completed
✓ Meet with your GP within the next two months to discuss your survivorship care plan and long term care
✓ Ensure you discuss with your GP a yearly flu & 5 yearly pneumococcal immunisation, starting from 6 months after treatment was completed

Referrals Made:

✓
✓
✓
Community Resources and Support Groups

**Leukaemia Foundation**  
Geelong Leukaemia Support Nurse  
Contact details - 03 5222 5977  
Online support group - [http://www.talkbloodcancer.com/user](http://www.talkbloodcancer.com/user)

**Cancer Council - Victoria**  
Cancer Helpline – telephone support & cancer council directory service  
Cancer Connect - telephone support  
Contact Details – 13 11 20 or [www.cancervic.org.au](http://www.cancervic.org.au)

**The Australian Cancer Survivorship Centre**- [www.petermac.org/cancersurvivorship](http://www.petermac.org/cancersurvivorship)

**General recommendations for your ongoing health and well-being**

Continue to attend follow-up with your GP and Barwon Health specialists

Aim for long term optimal health and wellbeing- [www.jeanhailes.org.au](http://www.jeanhailes.org.au)


Be physically active for 20-30 minutes most days of the week- [www.cancervic.org.au/preventingcancer/](http://www.cancervic.org.au/preventingcancer/)
### Your Shared Care Partners

<table>
<thead>
<tr>
<th>General Practitioner</th>
<th>Survivorship Clinic Nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;Referring Physicians - Name and Address (Default)&gt;</td>
<td>Donna Lever</td>
</tr>
<tr>
<td>Andrew Love Cancer Centre</td>
<td>Andrew Love Cancer Centre</td>
</tr>
<tr>
<td>70 Swanston Street, Geelong 3220</td>
<td>70 Swanston Street, Geelong 3220</td>
</tr>
<tr>
<td>Ph 4215 2788</td>
<td>Ph 4215 2788</td>
</tr>
<tr>
<td>Email: <a href="mailto:survivorship@barwonhealth.org.au">survivorship@barwonhealth.org.au</a></td>
<td>Email: <a href="mailto:survivorship@barwonhealth.org.au">survivorship@barwonhealth.org.au</a></td>
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Signed:  
Date:  

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<thead>
<tr>
<th>Cancer Specialist Team</th>
<th>Cancer Survivor</th>
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<tbody>
<tr>
<td>&lt;Primary Care Physician - Name (Default)&gt;</td>
<td>&lt;Full Name&gt;</td>
</tr>
<tr>
<td>Andrew Love Cancer Centre</td>
<td>70 Swanston Street, Geelong 3220</td>
</tr>
<tr>
<td>Ph. 4215 2700</td>
<td>Ph. 4215 2700</td>
</tr>
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</table>

Signed:  
Date:  

### Health Diary & Symptom Records

<table>
<thead>
<tr>
<th>Date</th>
<th>Symptoms experienced</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
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### Current Medications

<table>
<thead>
<tr>
<th>Start Date</th>
<th>Medication &amp; Rationale</th>
</tr>
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<tbody>
<tr>
<td></td>
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</table>

**Note:** For the purpose of this appendix The Health Diary and Symptom Record and Current Medications tables have been reduced in size.
**GP non-Hodgkin lymphoma surveillance schedule**

Yearly Andrew Love Cancer Centre review (next appointment 15/5/14) with alternating yearly review requested with GP

**Rapid re-referral** - can occur by contacting the Survivorship Nurse on Ph. ------- or the Haematology team at Andrew Love Centre on (03) 4215 2600

<table>
<thead>
<tr>
<th>A guide to potential late and long term side effects of treatment</th>
<th>GP investigations-yearly review</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Second Malignancy</strong></td>
<td>Assessment - Careful history and physical examination- lymphadenopathy, hepatomegaly, splenomegaly</td>
</tr>
<tr>
<td>- Solid tumours: especially &gt; 10years ☐ breast ☐ lung ☐ skin ☐ colon</td>
<td><strong>Tests</strong> – FBC, U &amp; E, LFT including serum LDH, lipids, Beta 2 micro globulins</td>
</tr>
<tr>
<td>- Haematological: MDS/leukaemia, (peak 5-9 years)</td>
<td>Immunisations- influenza, pneumococcal – commence 6 months post treatment</td>
</tr>
<tr>
<td><strong>Cardiovascular disease</strong></td>
<td>Bone health, including vitamin D levels- 12 monthly</td>
</tr>
<tr>
<td>- Delayed heart failure (anthracycline related)</td>
<td>Dental health checks- 12 monthly</td>
</tr>
<tr>
<td>- Accelerated atherosclerosis (radiation), including carotids, atherosclerosis</td>
<td>Skin examination (with a focus on irradiated field)- 12 monthly</td>
</tr>
<tr>
<td><strong>Pulmonary dysfunction</strong></td>
<td><strong>As appropriate</strong></td>
</tr>
<tr>
<td>- Acute: radiation pneumonitis</td>
<td>Breast screen from 40, or from 25 (if &gt; 8yrs after chest irradiation)</td>
</tr>
<tr>
<td>- Chronic: pulmonary fibrosis, bronchiectasis, chronic pleural effusions</td>
<td>Endocrine function ☐ Thyroid ☐ Glucose intolerance/diabetes</td>
</tr>
<tr>
<td><strong>Infertility and endocrine dysfunction</strong></td>
<td>Annual ECG if other risk factors</td>
</tr>
<tr>
<td>- Gonad dysfunction</td>
<td><strong>Psychosocial review</strong></td>
</tr>
<tr>
<td>- Hypothyroidism</td>
<td>Healthy lifestyle- diet, reconditioning and exercise</td>
</tr>
<tr>
<td>- Premature menopause</td>
<td>Cancer related fatigue</td>
</tr>
<tr>
<td><strong>Neurologic and muscular complications</strong></td>
<td>Cancer distress and fear of cancer recurrence</td>
</tr>
<tr>
<td>- Chemo- associated neuropathy</td>
<td>Carer support</td>
</tr>
<tr>
<td>- Cervico-scapular muscle atrophy</td>
<td>Return to activities of daily living and work</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td>Sexual functioning</td>
</tr>
<tr>
<td>Cognitive Changes</td>
<td>Abuse behaviour cessation ☐ Smoking ☐ Alcohol ☐ Illegal or prescription drugs</td>
</tr>
<tr>
<td>cataracts</td>
<td></td>
</tr>
<tr>
<td>Chronic fatigue</td>
<td></td>
</tr>
<tr>
<td>sexual dysfunction</td>
<td></td>
</tr>
<tr>
<td>Avascular necrosis (of the hip)</td>
<td></td>
</tr>
<tr>
<td>lymphoedema</td>
<td></td>
</tr>
<tr>
<td>Increased risk of infections – asplenism or hypersplenism</td>
<td><strong>Signs &amp; Symptoms of Recurrence</strong></td>
</tr>
<tr>
<td>Firm painless swollen lymph nodes</td>
<td>Unintentional weight loss</td>
</tr>
<tr>
<td>Night sweats</td>
<td>Persistent loss of energy</td>
</tr>
<tr>
<td>Generalised itching</td>
<td>Rising LDH</td>
</tr>
<tr>
<td>Blood test abnormalities</td>
<td>Rising LDH</td>
</tr>
<tr>
<td>New symptoms – shortness of breath, pain, bloating</td>
<td><strong>References</strong></td>
</tr>
</tbody>
</table>

- NCCN Clinical Practice Guidelines in Oncology
## Appendix 5 Project Resources Developed

<table>
<thead>
<tr>
<th>Resource/ Validation and evidence base</th>
<th>Target audience</th>
</tr>
</thead>
</table>
| **1. Tumour specific survivorship care plans** for Breast, Hodgkin Lymphoma, non-Hodgkin Lymphoma, Head and Neck Cancers, Colorectal, Brain, Bladder and Ovarian Cancers | - Survivors  
- GPs and Practice Nurses |
**Children Oncology Group Guidelines for late effects:** [http://www.survivorshipguidelines.org/](http://www.survivorshipguidelines.org/) | |
| **2. GP tumour specific surveillance schedules** for Breast, Hodgkin Lymphoma, non-Hodgkin Lymphoma, Head and Neck Cancers, Colorectal, Brain, Bladder and Ovarian Cancers | - Primary Care Providers  
- Available also to survivors |
**NCCN Clinical Practice Guidelines in Oncology;** [http://nccn.org/professionals/physician_gls/f_guidelines/asp#site](http://nccn.org/professionals/physician_gls/f_guidelines/asp#site)  
**Children Oncology Group Guidelines for late effects:** [http://www.survivorshipguidelines.org/](http://www.survivorshipguidelines.org/) | |
| **3. GP Introduction to Survivorship letter** | - GPs and Practice Nurses |
| **Barwon Medicare Local/Andrew Love Cancer Communication Report; 2006**  
**General Practice Victoria** | |
| **4. Survivorship service flier- Appendix 19** | - Cancer specialists  
- Eligible survivorship candidates |
| - Varied sources  
- Consumer input | |
| **5. Radiation late effects report- Appendix 20** | - Radiation therapists  
- Survivorship Nurse |
| **Children Oncology Group Guidelines for late effects:** [http://www.survivorshipguidelines.org/](http://www.survivorshipguidelines.org/) | |
| **6. General health assessment- Appendix 10** | - Survivor (assessment tool) |
| **Peter Mac supportive care assessment tool**  
**The Australian Type 2 Diabetes Risk Assessment Tool AUSDrisk;** Heartrack Cardiovascular Risk Assessment, Barwon Health 2013 | |
## Appendix 6 Communication Strategies

<table>
<thead>
<tr>
<th>Communication method</th>
<th>Target audience</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Survivorship Flier</strong> - provided to patients by their</td>
<td>- Cancer Patients</td>
</tr>
<tr>
<td>specialist towards the end of their treatment or in</td>
<td>- Cancer Specialists</td>
</tr>
<tr>
<td>survivorship phase and provided as a project introduction</td>
<td>- Professionals as service introduction</td>
</tr>
<tr>
<td>and information sheet.</td>
<td></td>
</tr>
<tr>
<td><strong>2. Electronic newsletter</strong> – also available in hard copy</td>
<td>- CEOs, consumers</td>
</tr>
<tr>
<td>2 editions including posting on BSWRICS website and VSCP</td>
<td>- Key stakeholders</td>
</tr>
<tr>
<td>shared online site.</td>
<td>- Survivorship Community of Practice</td>
</tr>
<tr>
<td><strong>3. GP and Practice Nurse Newsletters</strong> – Barwon</td>
<td>- GPs, Practice Nurses, Managers</td>
</tr>
<tr>
<td>Medicare Local</td>
<td></td>
</tr>
<tr>
<td><strong>4. BSWRICS Annual report</strong> : Ryan’s story: a consumer</td>
<td>- CEOs, consumers</td>
</tr>
<tr>
<td>perspective of the survivorship project  <strong>Appendix 8</strong></td>
<td>- Key stakeholders</td>
</tr>
<tr>
<td><strong>5. BSWRICS Governance Group Meetings</strong>: regular agenda</td>
<td>- BSWRICS Governance Group</td>
</tr>
<tr>
<td>item</td>
<td></td>
</tr>
<tr>
<td><strong>6. RICS Supportive Care Meetings</strong>- regular agenda</td>
<td>- RICS supportive care staff</td>
</tr>
<tr>
<td>report</td>
<td></td>
</tr>
<tr>
<td><strong>7. Winner</strong>-Barwon Health, Health Care Innovation</td>
<td>- Barwon Health CEO, department leaders</td>
</tr>
<tr>
<td>Awards 2013</td>
<td></td>
</tr>
<tr>
<td><strong>8. Geelong Advertiser</strong>- article refers to survivorship</td>
<td>- General Public</td>
</tr>
<tr>
<td>project. Wednesday 22 August 2013</td>
<td></td>
</tr>
<tr>
<td><strong>9. Committee member</strong>- BH Smoking cessation service</td>
<td>- BH services</td>
</tr>
<tr>
<td></td>
<td>- Consumers and general public</td>
</tr>
<tr>
<td><strong>10. Project summary – 2 paragraph Appendix 22</strong></td>
<td>- General Public Press release</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>11. Project summary – 1 page Appendix 23</strong></td>
<td>- General public</td>
</tr>
<tr>
<td></td>
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</tr>
<tr>
<td><strong>13. FCIC Survivorship conference</strong>, Glenelg, South</td>
<td>- The Challenge of developing a nurse led survivorship</td>
</tr>
<tr>
<td>Australia, February 1-3, 2013</td>
<td>model of care - initiating a service within a</td>
</tr>
<tr>
<td>Poster Presentations</td>
<td>rural and regional health care service.</td>
</tr>
<tr>
<td></td>
<td>- Implementing a survivorship service for patient</td>
</tr>
<tr>
<td></td>
<td>with head and neck cancer- are some cancer</td>
</tr>
<tr>
<td></td>
<td>survivors more forgotten than others</td>
</tr>
</tbody>
</table>
Appendix 7. Survivorship Article - BSWRICS Annual Report

TELEMEDICINE PILOT

In 2013, as an innovative means to both improve and further develop service delivery for rural patients, Barwon Health Cancer Services in collaboration with Portland District Health and Western District Health Services have undertaken a telemedicine pilot program. The program aimed to substitute the travel undertaken by patients to Geelong by providing review appointments via video link. Professor David Ashby and Dr Mustafa Khawar, Barwon Health oncology consultants, led the initiative supported by Cancer Link Nurses, Specialist Clinic staff and BSWRICS.

The model consists of the following:

- The centres are identified as suitable for a telemedicine review by their doctors and subsequently consent to having an appointment via video link.
- An oncologist situated in the Andrew Navy Cancer Centre video links via their computer to a specially equipped room at other sites.
- Patients are free to ask questions of the doctor as would happen in a face to face appointment.
- There are no out of pocket expenses to patients for a telemedicine appointment.
- Early in the Pilot, an audit of equipment and technology was undertaken at all participating sites to ensure needs and identify gaps. Interviews with relevant personnel were carried out to understand and address the concerns of each service.

90% OF PATIENTS THOUGHT THE VIDEO CONSULTATION SAVED THEM TIME AND MONEY COMPARED TO A FACE-TO-FACE VISIT

SURVIVORSHIP CARE

Cancer survivorship is now recognised as a distinct phase of cancer care. More people are being cured of cancer and are living as survivors of cancer, primarily due to advances in cancer treatment.

Survivorship is a term used to describe the phase of care that follows primary treatment. While acknowledging every person’s experience is unique, it is now accepted cancer and cancer treatment may have a number of impacts on physical, social and psychological health and wellbeing. Not all impacts are negative - many cancer survivors benefit from ongoing assistance after treatment is completed. Issues experienced may include pain, fatigue, lymphoedema, cognitive changes and difficulties re-attaining health and fitness to return to employment and daily activities. Psychological distress, fear of cancer recurrence, changes in body image and existential questions about life after cancer are also often experienced. Cancer and cancer treatments are recognised to have potential late and long term effects that require ongoing surveillance and a coordinated approach from specialists, General Practitioners, rehabilitation, allied health and community services.

Commencing in May 2012 Barwon South Western Regional Integrated Cancer Service, with partners Barwon Health, Barwon Medicare, Local, Western District Health Service and Deakin University, has lead and implemented a cancer survivorship project. One of 6 state-wide survivorship pilot projects funded by the Victorian Department of Health, the project aims to improve the health and wellbeing of survivors of cancer. This is achieved through the implementation of a nurse led survivorship clinic and improved communication and service pathway between cancer specialists, General Practitioners, allied health and community services. To date, survivorship nurse-led clinics have been attended by a total of 57 patients in Geelong, Warrnambool and Colac. Patients have received a written care plan summarising their treatment, a recommended follow-up plan and information and education focusing on maintaining and improving their health after treatment.

Deakin University is gathering information from participants and staff to measure how the new model of care has contributed to the lives of survivors and to assess economic and service delivery questions. Initial evaluation indicates a high level of acceptance for the survivorship service with survivors reporting that the clinic helped them to understand their follow up care, manage symptoms and side effects, feel more in control of their lives and recognise signs for follow up with a General Practitioner or specialist. The survivorship care plan helped reduce their concerns, helped them cope with treatment and to feel positive about moving forward. More than 50% of people attending the survivorship clinic have been linked with health services in the community to promote their ongoing physical and psychological health.

Planning is occurring to enable this valuable to continue as a component of quality cancer care.

MORE THAN 50% OF PEOPLE ATTEndING THE SURVIVORSHIP CLINIC HAVE BEEN LINKED WITH HEALTH SERVICES IN THE COMMUNITY TO PROMOTE THEIR ONGOING PHYSICAL AND PSYCHOLOGICAL HEALTH.
RYAN’S STORY

I have worked really hard to regain my mobility after treatment. Walking has been very difficult, and I needed a walking stick for some time.

In early 2011, creative firefly Ryan Trickey was embracing life like any enthusiastic 20 year-old with a passion for the arts. By day, he was actively pursuing his first love, studying graphic design, and by night he was drumming in a band.

When Ryan felt some pain in his lower right leg, he initially brushed it off as a minor sprain from hitting the kick drum too hard, but when the pain didn’t naturally subside, he decided he should seek medical advice.

There was no speedy diagnosis, and what followed was nine months of moving from one doctor to the next in search of answers. Finally, a blood scan revealed the hidden truth; that Ryan was suffering from an unusual form of blood cancer, essential thrombocythemia, below his right knee.

Ryan refuses to see it as being retired with a metal uptake as he immediately began a six-month treatment program of chemotherapy and radiotherapy. He was forced to pull his studies and stop playing in the band.

Thankfully, since completing treatment in February 2012, Ryan’s cancer is in full remission. But 20 months later, he is still very much feeling the effects.

“I need a lot of sleep every day. The main thing is feeling tired all the time, and the lack of concentration. From what I've been told, it’s a side effect from the treatment,” Ryan said. “I have noticed really hard to regain my mobility after treatment. Walking has been very difficult, and I needed a walking stick for some time.”

Ryan became an early participant in a new survivorship project established in our region by BSWRCS's.

Ryan was assisted by a dedicated survivorship nurse to help ensure he received the follow-up care he needed and support to access rehabilitation services. He was provided with medical information and resources. A communication between his cancer specialists, GP and healthcare professionals and community services were strengthened.

Ryan still remembers the day he met survivorship nurse, Donna Lacey, who has since played a significant role in helping him regain the use of his leg, getting his pain under control and his life back on track.

“I had no-idea of the survivorship program before. But when we met Donna, everything changed. She was friendly and caring, and while it might sound like a small thing, she wanted to know my name and what was important to me.

“Donna got me in to see several specialists, organised a physio, hydrotherapy sessions and even got me in touch with a pain management program. She even put me in touch with a GP who really understood my situation.”

It’s still early days, but Ryan says the survivorship project has been incredibly beneficial in helping him regain his physical fitness, and to develop ways to cope.

They say it’s five years for a full body recovery, but with the help of the survivorship project I have been able to resume my life.
## Presentations and training

<table>
<thead>
<tr>
<th>Presentations and training</th>
<th>Target audience</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Introduction to survivorship</strong>: tailored to needs of each professional group.</td>
<td>• Cancer specialists, cancer nurses, breast care nurses, radiation therapists, allied health providers, multidisciplinary team meetings</td>
</tr>
<tr>
<td><strong>2. Non Hodgkin lymphoma</strong>: Post treatment management in General Practice and an introduction to survivorship care. (In conjunction with BML).</td>
<td>• GPs</td>
</tr>
<tr>
<td><strong>3. Survivorship Care</strong>: Developing pathways of communication and shared care.(In conjunction with BML).</td>
<td>• Barwon Medicare Local GP Advisory Committee</td>
</tr>
<tr>
<td><strong>4. A new focus of care</strong>: Applying a chronic disease management approach for survivors of cancer (CCV training program utilised). (In conjunction with BML).</td>
<td>• GP Practice Nurses</td>
</tr>
<tr>
<td><strong>5. Introduction to the Survivorship Project.</strong></td>
<td>• Geelong Prostate Support Group Forum 2012</td>
</tr>
<tr>
<td><strong>6. BSWRICS Education Forum.</strong> Survivorship a New Model of Care 20/3/13</td>
<td>• Cancer Nurses and Specialists, Allied Health providers, pharmacists</td>
</tr>
<tr>
<td><strong>6. Health Round Table- Improving management of patients living with cancer. 5 and 6 Sept 2013. Presentation</strong></td>
<td>• Cancer Professionals • Consumer representatives</td>
</tr>
<tr>
<td><strong>PC4 Concepts Development Workshop. Barwon South Western Survivorship Project Presentation, 18 September 2013.</strong></td>
<td>• PC4 members, Research Professionals and General Practitioners</td>
</tr>
<tr>
<td><strong>6. ACSC Consumer Survivorship Forum. 12 December 2013</strong></td>
<td>• Consumers</td>
</tr>
<tr>
<td><strong>7. Colorectal Conference- Peter MacCallum Cancer Centre, Pioneering Survivorship Providing care to patients’ of regional &amp; rural South-west Victoria. 20/3/14</strong></td>
<td>• Medical, nursing and other health professionals</td>
</tr>
<tr>
<td><strong>8. BSWRICS - Consumer Survivorship Forum- 28 March 2014</strong></td>
<td>• Consumers, cares, professionals</td>
</tr>
<tr>
<td><strong>9. ACSC Professionals Forum- Final project presentation, 28 March 2014</strong></td>
<td>• Health Professionals</td>
</tr>
<tr>
<td><strong>Presentation planned- 7. “Survivorship Care”- Applying a chronic disease management approach and engaging Allied Health in improved health outcomes for</strong> (April 2013)</td>
<td>• Allied Health Professionals</td>
</tr>
</tbody>
</table>
Appendix  10 General Health Assessment

Your Individual Health Assessment

Health Care Card/Pension Card/Single parents  (please circle answer)

Do you have any goals you would like to focus in your life after cancer?  
✓
✓

Current Ht- Wt- Waist measurement –

Have you noticed any weight changes since commencement of treatment?

Family Health History – cancer  ○ cardiac  ○ hypertension  ○
diabetes  ○ other  ○

How many times a day do you eat vegetables?
5+ serves/ day
to 1-3 serves/day
I rarely eat vegetables

How would you describe your level of activity?
Walk to the mailbox each/most day/s
Active within the house/yard
Walk around the block each/most day/s
Walk 20 mins most days
Complete a regular exercise program

How often does your exercise include weight bearing activity?

How often do you have a drink containing alcohol?
4 +times a week
2-3 times a week
2-4 times a month
mthly or less
Never

How often do you smoke any tobacco products?
Everyday
4-5 times a week
1-2 times a week
mthly or less
Never

How often do you take non- prescription medicines? e.g. paracetamol, vitamins, naturopathy
4 +times a week
2-3 times a week
2-4 times a month
mthly or less
Never

How often do you take recreational drugs? – E.g. marijuana, amphetamines etc.
4 +times a week
2-3 times a week
2-4 times a month
mthly or less
Never

Sexual Health

Have you recently gone through menopause?
Yes (refer to menopause rating scale)  No  Unsure  N/A

Has the effect of your treatment on your fertility been discussed with you?
Yes  No  Unsure

Are you currently using hormone therapy?
Yes  No  Unsure  N/A

Do you have a partner?
Yes  No

Do you have any sexual function problems?
Yes  No  Unsure

Are you currently sexually active?
Yes  No  I would like to be

Nurse Led Assessment – Survivorship Health & Well Being
Adapted from Peter Mac Supportive Care Assessment Tool; Hearttrack Cardiovascular Risk Assessment, Barwon Health; The Australian Type 2 Diabetes Risk Assessment Tool (AUSDRISK), Dept of Health and Ageing, Australian Government
Distress Management

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

**SCREENING TOOLS FOR MEASURING DISTRESS**

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week, including today.

**Practical Problems**
- Child care
- Housing
- Insurance/financial
- Transportation
- Work/school

**Family Problems**
- Dealing with children
- Dealing with partner

**Emotional Problems**
- Depression
- Fears
- Nervousness
- Sadness
- Worry
- Loss of interest in usual activities

**Spiritual/religious concerns**

**Physical Problems**
- Appearance
- Bathing/dressing
- Breathing
- Changes in urination
- Constipation
- Diarrhoea
- Eating
- Fatigue
- Feeling Swollen
- Fevers
- Getting around
- Indigestion
- Memory/concentration
- Mouth sores
- Nausea
- Nose dry/congested
- Pain
- Sexual
- Skin dry/itchy
- Sleep
- Tingling in hands/feet

Other problems: ____________________________________________
Appendix 6 continued


These Guidelines are a work in progress that will be refined as often as new significant data becomes available.

“The NCCN Guidelines are a statement of consensus of its authors regarding their views of currently accepted approaches of treatment. Any clinician seeking to apply or consult any NCCN guideline is expected to use independent medical judgement in the context of individual clinical circumstances to determine any patient’s care or treatment. The National Comprehensive Cancer Network makes no warranties of any kind what so ever regarding their content, use or application and disclaims any responsibility for their application or use in any way.”

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Appendix 12 Pamela’s Story.

Pamela’s Story- presented to the Australian Cancer Survivorship Centre Consumer Forum
12 December 2013

My name is Pamela and the only reason I have the strength to talk to you today is because of the empowerment that my survivorship program gave me.

As a 24 year old I was diagnosed with cancer in 2010 and underwent 3 years of non-stop treatment – chemo, radiotherapy and transplants. The time after treatment stops is difficult and something that not many people can quite understand unless they have been through it themselves. After spending 3 years in the hospital environment where cancer is your life every single day, it is really hard to return to normal life again.

A diagnosis of cancer uproots you from your world and when treatment finishes you’re thrown back into the real world again. It is extremely overwhelming, I felt like I was being left to fend for myself, but had no idea what to do. I had no control or direction in life. I had been so dependent on those around me. I was lost. I was frustrated a lot of the time and would cry almost on a daily basis. I lashed out at my family and although I could see the relationships breaking down … but I couldn’t help myself. Emotionally I was all over the place and my family had no idea how to deal with it. Getting over treatment wasn’t just physical it was also dealing with all the emotions from the past few years.

And then I was introduced to Donna at the Survivorship clinic. Without exaggeration my life changed from that first meeting onwards and things only began to improve from that point. The survivorship program helped me in many aspects of my life and gave me a general direction and a regain of control. One of the most powerful outcomes for me was being connected to an exercise program especially for cancer patients called Strive 2 Thrive. The benefits were not only physical but emotional too. I was very thin and had lost 15kg in weight and was struggling with my body image, self-esteem and confidence. None of my clothes fitted me anymore. I knew in the back of my mind that doing rehabilitation would be important but again I just didn’t know where to go and what my body could handle. I didn’t want to join an ordinary gym with a standard trainer because I knew that they wouldn’t know what to do with me, I wouldn’t be an ordinary client with the after effects of cancer treatment.

There are many services available out there but as a patient who was new to it all I had no idea that they existed. And that’s why having someone like Donna to help put you in the right direction is a massive help.

Below is a small section of a thank you card that I wrote to the organisers of the exercise program I attended;

“The exercise program really was a life saver. I have noticed a huge difference in the way I feel both physically and emotionally since I started. I look and feel better and stronger, which has given me more confidence. I was even able to enjoy a recent trip to Tasmania and walked the 45 minutes uphill to the Wineglass Bay lookout, which is a huge achievement for me since the same time last year it was literally tiring to take a shower”.

In the 3 months the changes have been so dramatic and it has made me so happy. My fatigue has improved, energy levels improved and I have regained muscle strength and weight.”

Survivorship programs need to be seen in the medical world as an extension to treatment that every patient needs to go through. I am very grateful and as an advocate I want to make sure that these programs continue.
Appendix 13 Glenda’s Story

Glenda’s story - presented to the Australian Cancer Survivorship Centre Consumer Forum
12 December 2013

Hi my name is Glenda and I attended the survivorship program 3 years after my treatment had stopped. I found out on the 3rd of February 2010 when I discovered a dry lump in my throat and it turned out to be a squamous cell carcinoma on my left tonsil.

My job at that time was as a marketing consultant in shopping centre management & I also coordinated middle and major special events. My work was an important part of who I was, I had a complicated role with lots of responsibility & one where many things were always happening at once. With an 11 month old grandson - life was good!

My treatment was a very painful peg tube insertion, 35 radiotherapy treatments over 7 weeks, with 3 rounds of chemotherapy & was finally completed 6 months later with the removal of my PEG tube. Treatment had taken me from being an independent person to someone who was dependant on my carer, my husband. At my lowest point I couldn’t feed myself & I had lost 23kgs. I’d gone from this independent and successful person to someone who sat and slept in the recliner, couldn’t go to the toilet myself and had lost control of all bodily functions.

My husband nursed me 24/7 and took time away from his job for 8 months. The financial burden of me not working and the cost of medical expenses impacted heavily on our lives. My husband had become my nurse, my carer, my cleaner, my guardian and my emotional support. He carried the burden and I carried the guilt. We were so glad when treatment finished. I would not see my specialist for 3 months. But I was still so unwell and my husband was expected to take care of me with no training and little support. “We felt the rug being pulled out from under our feet again”.

Three years on - I was still struggling, “we felt like we were climbing up a mountain by our fingernails. One day I walked into my specialist’s office and he said “I can feel your stress and I haven’t even looked at you yet”. He referred me to the survivorship program and I met Donna the following Monday.

I have to say revisiting the cancer treatment was very confronting. It was painful and I cried a lot and it really hurt to remember what I had been through but for the first time I could talk about it.

We talked about the possible late effects of my treatment and how to work through it with my health team and GP, and ways to keep myself healthy. After my visit I also took on the option of some counselling. It was a turning point for me, it was then that I started to heal. It didn’t happen overnight but it did happen.

I feel that the patient’s time from treatment to survivorship needs to be clearer to ensure the care survivor’s needs comes at an appropriate time. Cancer survivors have ongoing, strange and unusual needs with many financial costs; such as costs for aids to live well and visits to multiple specialists. For example I need special shoes to help me walk without pain. There are currently no government schemes to access to help cancer survivors to live well.

Life is good again – although I have not returned to work I can see new roles for me. I am loving caring for my grandchildren and am looking forward to more travel with my husband. I feel my future is bright.
Appendix 14 GP letter - Project introduction, including agreement to share cancer care (if appropriate)

Cancer Survivorship Project.
Improving Health and Well Being for Survivors of Cancer

Dear <GPs name>,

<Patients full name in bold> has participated in the Cancer Survivorship Project. This project, one of 6 in Victoria funded by the Department of Health, aims to improve outcomes for cancer survivors and includes the assessment of patient post treatment needs and risks, a nurse led survivorship care plan and strengthening of communication pathways between cancer specialists and GPs.

Attached is a
- **GP surveillance schedule**, designed with input from GPs and cancer specialists to assist in ongoing post treatment care.
- **Survivorship Care Plan** established with the patient to empower them in their health and wellbeing.

Please sign and return to indicate your willingness to share post treatment follow-up, as outlined in the specialist’s letter of May 31 (a copy is attached for your reference).

Recall of patients who fail to attend an appointment is recommended
If you have any questions or concerns please contact the specialist directly or the Survivorship Nurse
Ph. 0401 011 661 or survivorship@barwonhealth.org.au

Dr <GPs first name and surname>  Signature________________  
Date________________

Research suggests that many survivors live with chronic treatment morbidities and long term health issues. Electronic transfer of documents is currently being developed, and may facilitate ongoing patient disease management planning.

**We highly value your input in implementing this project.**
Please take 30 seconds to complete and return using the addressed envelope.

1) Is the **surveillance schedule** useful to the ongoing care of this patient?  Yes [ ]  No [ ]
2) Is the **surveillance schedule** in a useful format?  Yes [ ]  No [ ]
3) Is the **Survivorship Care Plan** useful in the ongoing care of this patient?  Yes [ ]  No [ ]

Comments and suggestions______________________________________________

Thankyou
Kate Schofield – Ph.  Fax  Email
Andrew Love Cancer Centre, Barwon Health 70 Swanston St, Geelong, 3220
Appendix 15 Project Evaluation Structure

**Patient is identified** by Survivorship Nurse and Oncologist towards end of treatment stage involving chemotherapy and/or radiotherapy or early in survivorship phase.

**Patient is introduced to Survivorship project by** Cancer Specialists once the end treatment has been established.
Oncologist refers patient to Survivorship Nurse.
Survivorship Nurse invites patient to be involved in the study and to complete consent / baseline Q.
Consent and Baseline questionnaire is placed in sealed envelope by the patient and given to Survivorship Nurse or front desk for posting to Deakin.

**Interview 1.**
Survivorship Nurse Assessment is commenced with Survivorship Nurse

**Interview 2.** Patient attends Survivorship Nurse Clinic to complete individualised Care Plan, receive education, support and referral on to allied health and community services. Survivorship Nurse has communicated prior to interview 2 with GP and gains sign-off of post treatment plan from lead cancer specialist.

Patient receives follow up care according to level of need and risk
- Specialist Care
- Shared Care
- GP Led Care

Follow up Survey to Health Professionals involved in survivorship services re work force: patient outcomes, level of success and acceptance, outcomes of shared care Survivorship nurses GPs Allied health Cancer and specialist nurses Cancer specialists, radiation therapists Psychologists.

3 months later
Patient mailed follow up Questionnaire:
- heiQ
- HLQ
- AQoL
- Satisfaction with survivorship service
Patient completes questions and returns to Deakin University in a reply paid envelope.
Appendix 16 Summary of sustainability strategies

Sustainability strategies are included as part of the description of each project objectives in main report.

Summary of sustainability strategies

**Technology**

Utilisation of electronic recording, storage and transmission of survivorship documents contributes to time savings, and improves electronic transfer capabilities. Additional electronic systems are available and offer opportunities (CHARM, MDMs e-record). Electronic programs that allow dynamic sharing of information will improve service coordination particularly in the transmission of documents from cancer centre to GPs. Telehealth (phone service) offers potential for regional and remote participants.

**Cancer specialists and centre**

Development of cancer specialists as survivorship ‘champions’ is a key to ongoing success and engaging in a high level of collaboration and communication over time is essential. Building on existing processes increases acceptance and saves time e.g. a short trial of a new and separate survivorship referral form was poorly accepted and utilised so discontinued.

Survivorship appointments can be lengthy when patients have complex needs and high levels of distress. A focus on triage with referral onward to rehabilitation and community services is recommended eg psychology, counselling, and psycho-oncology. Livestrong and electronically available survivorship programs may offer advantages when used in conjunction or as an alternative to face to face survivorship (reduce time commitment) and when project referrals exceed nurse survivorship clinic capacity.

**Cancer Survivors**

A focus on increasing participants’ confidence and skills in assisted self-management led to successful outcomes and is particularly relevant where provision of ongoing follow up survivorship services are not economically sustainable in the present fiscal environment. Group led sessions could provide common messages (health education, diet) effectively.

**Engagement of Primary Care Providers**

Incorporating concepts of survivorship (as appropriate) and raising the importance of having contact with a GP could be presented at earlier times in the patient’s care.

Inclusion of cancer into allied health priority and intake systems will increase access by survivors to Community Health services. Increasing access to, and building on existing service models (e.g. the Community Health Service Model) appears more sustainable than gaining funding for the development of “cancer survivor” specific service. A physiotherapy provider in Colac has commenced a reconditioning and exercise group for cancer survivors based closely on a similar program for cardiac patients. Continuing identification of regional resources will create a more detailed network. Services can often be gained more quickly through private services and access to GPCDMPs.

Increased engagement of GPs in survivorship care promotes patient, GP and cancer specialist confidence in long term survivor follow up care (e.g. 10, 20, 30 years later). Greater engagement of practice nurse roles in chronic care management of patients has the potential to strengthen transition pathways and continue care. Assisting in the design of a GPCDMP for survivors, aligned with survivorship care plans will aid information transfer between service providers. Continue development of electronic communication pathways between specialist and PCPs e.g. cdmNet (a multi user program) is required.

Continued engagement with Medicare Local projects will strengthen Survivorship presence in health discussion and development. Opportunity exists to make greater use of MBS funding including Telelink services for patients who have compromised mobility or live in remote area and GP phone involvement in
survivorship care planning. Greater clarity regarding professional roles, responsibilities and medico legal requirements will produce more acceptance and confidence regarding patient outcomes.
Appendix 17 Key Steps to consider when implementing this model.

The project report provides an overview to consider and key steps applicable when implementing a similar project across other sites or regions.

The following points are also provided to assist

- Prepare the theoretical base for the project thoroughly and avoid pressure to start up new clinics quickly.
- Clarify aims and objectives and utilise these to guide project direction and decision making throughout.
- Survivorship is a very new domain and utilises different models of care to clinical work, so ensure team members receive training and development including review of literature, survivorship education and professional networking.
- Identify key stakeholders including consumers.
- Invite input and listen to specific interests, and motivations of key stakeholders.
- Avoid presenting a prearranged project plan as this can create initial resistance.
- Be prepared to modify plans depending on key stakeholders input and responses.
- Create a context of collaborate and support. Avoid appearing to compete with physicians.
- Be aware of strengths and weaknesses of the existing service structure and community.
- Align with successful projects and initiatives already existing
- Utilise existing tumour stream process, organisational processes and communication structures. (Don’t reinvent the whole wheel and avoid developing further paperwork to be completed).
- Achieve initial small successes and build on these.
- Take every opportunity to repeat your messages and talk about survivorship.
- Be seen and create a presence both formally and informally (in the staff kitchen).
- Promote introduction of survivorship early in the patients care.
- Identify and cultivate survivorship champions and leaders.
- Consider the language used and how this is interpreted and understood differently by different professionals.
- Look for ways to create sustainability and save the service money (e.g. discharge of patients).
- Keep documents short (one page is preferred by GPs and cancer specialists).
- Use consumer friendly language in documents produced for consumers.
- Collect and disseminate data to provide an evidence base and to enhance acceptance.
Survivorship Clinic

Have you finished your treatment and not sure what happens next?

The Survivorship Clinic assists people to return to health and to the important things in life.

If you

- Have received chemotherapy and/or radiation therapy within the last 2 years?
- For non-Hodgkin lymphoma, Hodgkin lymphoma, breast, colorectal, or a head or neck cancer?
- and have now finished your treatment?

Ask your specialist about an appointment with the Survivorship Nurse who can assist you with

- an individual plan for your health
- information and support related to your health needs and goals
- information for your GP to enhance your post cancer life
- services that can assist you in your return to health

Donna Lever- Survivorship Nurse
Phone: 4215 2788
Email: survivorship@barwonhealth.org.au
Survivorship Care Planning
**Nasopharynx radiation late effects report**

<table>
<thead>
<tr>
<th>Patient Name: __________________________</th>
<th>Patient UR Number: ________________</th>
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Please indicate organs and structures which were included within the radiotherapy field and should be observed or monitored for late side effects:

<table>
<thead>
<tr>
<th>Organ/Structure</th>
<th>Yes</th>
<th>No</th>
<th>Maybe</th>
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<tbody>
<tr>
<td>Thyroid</td>
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<td>Parotid</td>
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<tr>
<td>Optic Nerves</td>
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<tr>
<td>Lens</td>
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</tbody>
</table>

Radiation Oncologist/Radiation Therapist:_______________________________________

Date:______________________________

Please refer any questions or discussion to the Survivorship Nurse: __________________
Appendix 21 Authorship

Project Authors:

Kate Schofield  Survivorship Project Manager  
Donna Lever    Survivorship Nurse  
Kate Morrissy  Program Manager, BSWRICS  
Marital Reed   Service Development Manager, BSWRICS  
Prof Trish Livingston  Associate Dean – Research, Faculty of Health, Deakin University  
Assoc Prof Cathy Mihalopoulos  Health Economics, Deakin University  
Dr Sophy TF Shih  Research Fellow, Health Economics, Faculty of Health, Deakin University

Appendix 22 Acknowledgments

The Survivorship Project wishes to acknowledge the work of the following individuals and groups:

All the participants of the Survivorship Pilot Project in Hamilton, Colac and Geelong  
Survivorship Project Board Members (Appendix 1)  
Jane Sharp Survivorship Nurse Western District Health Service  
Roger Northam, Faith Sutterby and Leanne Fagg Consumer Representatives  
The staff of the Andrew Love Cancer Centre  
The staff of Western District Health Service  
The staff of the Colac Area Health  
Michele Shields- IT support  
Dr Michael Homewood GP Representative  
Barwon South Western Regional Integrated Cancer Service team members  
The Australian Cancer Survivorship Centre  
Victorian Cancer Survivorship Pilot Project Community of Practice members  
Dr Theresa Leung – Consultant Haematologist  
The Barwon Medicare GP Advisory Group  
The Barwon Health GP Liaison Team  
Allied Health Professionals and GP Practice Nurses contributing to the project  
Pamela Bousejean and her brother Andrew Bousejean for designing the logo and artwork  
Glenda Ford, Pamela Bousejean and Ryan Trickey for their participant stories and presentations
The Barwon and South Western Survivorship Pilot Project designed and trialled Nurse Led Survivorship Clinics for survivors of cancer who have completed chemotherapy and radiation therapy. The survivorship nurse met with each participant to develop a written Survivorship Care Plan tailored to the person’s ongoing health needs, personal goals, specific cancer type and treatment they had received. A range of health information, and allied and community health referrals, were provided to assist participants to manage and maximise their return to health and wellness. The GP of each participant was contacted, provided cancer survivorship specific information and engaged in the ongoing care of the person.

Project participants reported a high level of satisfaction with the new service and reported the survivorship nurse help them to know where to gain further support; understand their follow up care, feel positive about moving forward, cope with finishing treatment and feel more control of their life. Cancer specialists reported the Survivorship Service improved post treatment care and GPs have reported the survivorship documents provided to them were useful to their ongoing care of the patient. The project report recommends that the survivorship service be made available to survivors of all types of cancers as well patients living long term with a cancer diagnosis and undergoing long term treatment.
Appendix 24. 1 page lay summary suitable for general public

Cancer survivorship is now recognised as a distinct phase of cancer care. More people are being cured of cancer and are living as survivors of cancer, primarily due to advances in cancer treatment.

Survivorship is a term used to describe the phase of care that follows primary treatment. Whilst acknowledging every person’s experience is unique it is now accepted cancer and cancer treatment may have a number of impacts on physical, social and psychological health and wellbeing. Not all impacts are negative, however many cancer survivors benefit from ongoing assistance after treatment is completed. Physical issues experienced may include pain, fatigue, lymphoedema, cognitive changes and difficulty regaining health and fitness to return to employment and everyday activities. Psychological distress, fear of cancer recurrence, changes in body image and existential questions about life after cancer is also often experienced. Cancer and cancer treatments are recognised to have potential late and long term effects that require ongoing surveillance and a coordinated approach from specialists, General Practitioners, rehabilitation, allied health and community services.

Commencing in May 2012 Barwon South Western Regional Integrated Cancer Service with partners Barwon Health, Barwon Medicare Local, Western District Health Service and Deakin University has led and implemented a cancer survivorship project as one of 6 Victorian Cancer Survivorship pilot projects funded by the Department of Health. The Barwon and South Western Survivorship Pilot Project has designed and trialled Nurse Led Survivorship Clinics for survivors of cancer who have completed chemotherapy and radiation therapy within the previous 2 years.

The survivorship nurse met with each participant to develop a written Survivorship Care Plan tailored to the person’s ongoing health needs, personal goals, specific cancer type and treatment they had received. A range of health information, and allied and community health referrals, were provided to assist participants to manage and maximise their return to health and wellness. The GP of each participant was contacted, provided cancer survivorship specific information and engaged in the ongoing care of the person.

Project participants have reported a high level of satisfaction with the service and report the survivorship nurse help them to know where to gain further support; understand their follow up care, feel positive about moving forward, cope with finishing treatment and feel more control of their life. Cancer specialists report the Survivorship Service has improved post treatment care and GPs have reported the survivorship documents provided to them have been useful to their ongoing care of the patient.

The project report recommends that the survivorship service be made available to survivors of all types of cancers as well patients living long term with a cancer diagnosis and undergoing long term treatment.
References

1. Australian Cancer Survivorship Centre, *Survivorship Care: What is it?*, In Touch, News from the Australian Cancer Survivorship Centre, Melbourne 2013.


11. PROSPECT Study 2009 BSWRCS.


17 Livestrong Foundation, Livestrong Care Plan accessed online 20/3/14 http://www.livestrongcareplan.org/


‘Treatment is just the tip of the iceberg, survivorship is what lies beneath the surface.’

Victorian Cancer Survivorship Program Pilot Project
Victorian Department of Health

Addendum to Final Report
18 June 2014
Review of Pilot Project Final Report – Barwon South West Region

Peer Review- Document 1.

The following numbered suggestions (in black font) were provided as part of the peer review process to strengthen the report. The project team’s responses are provided in blue.

1. The project demonstrated good uptake with generally good response rates to the evaluation surveys and tools. A diagram illustrating response rates for the survey and interviews across the three time points would add to the report.

<table>
<thead>
<tr>
<th>Response rates across project evaluation time points</th>
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<tr>
<td>Survivors approached to participate in the project and the project evaluation.</td>
</tr>
<tr>
<td>129</td>
</tr>
</tbody>
</table>

2. The authors’ state similar patient, professional and organisational systems and documentation were implemented across each of the 3 sites with flexibility to integrate local health service design, local knowledge and service networks. Some examples of what this flexibility means in practice, and guidance for others as to the issues to be considered here would be useful.

Examples of flexibility when implementing similar projects include:
2.1 Local health service design- e.g. recognising and understanding the organisational structure, patient records and data management systems, availability of electronic means, lines of accountability, current service delivered and missions and values of these services.
2.2 Local knowledge and interest- e.g. identifying potential survivorship’ champions’, professionals with relevant training and expertise, identifying strong consumer advocates, developing awareness of health networks, other existing or proposed service developments, and being aware of the political environment.
2.3 Service networks- e.g. knowledge regarding existing networks and partnerships, strengths and challenges of these, including across acute, outpatient, rehabilitation, local community and consumer sectors.

3. The use of patient centred and motivational interviewing approaches were reported to allow for discussion of sensitive health issues e.g. sexuality, quitting smoking and/or unhealthy weight range. Assisted self-management and patient empowerment and education approaches were also reported as being central service design and delivery. How was this implemented in the project? What training was provided and were any data collected to assess nurses’ compliance with this approaches in practice?
3.1 How was this implemented in the project?
From the initial project design phase these approaches were identified as fundamental to the project and service approach and most likely to result in the desired patient and service outcomes. Approaches were implemented by
- Utilising patient centred care plans specific to tumour type and individual patient health goals as the basis for survivorship assessment and intervention
- Utilising patient centred language and concepts in the delivery of services
- Clearly identifying the differences between empowerment and assisted self-management approaches from treatment and more ‘supportive’ care approaches.
- Utilising real survivors examples (without disclosing identity) when training and engaging in discussion with other health care providers

3.2 What training was provided?
- The Geelong based Survivorship Nurse attended a 3 hour motivational interviewing workshop
- Literature search and ongoing professional education continued throughout the project
- Project manager had considerable experience in delivery of patient centred and patient empowerment patient services.

3.3 Was any data collected to assess nurses’ compliance with these approaches in practice?
- No – the project was not designed to evaluate the nurse led approach to this level
- Nurse self-monitoring and self-reports indicate a consistent approach to delivery of nurse consultations did occur
- The number of referrals instigated for patients to follow up their own health care needs in the community indicates these approaches were put into practice.
- Participants reports in regards to the survivorship service indicate the impact of these approaches on patients knowledge and potential actions. (Final report page 22)

4. The clinic appeared to have had a positive impact on empowerment, as well as health literacy, specifically, feeling understood and supported by health care providers, having sufficient information being able to identify good information and reliable sources of information and improving their navigation of the healthcare system. Care needs to be taken to acknowledge the limitations of the survey data in drawing this conclusion. In the absence of a comparison group, any conclusions re changes associated with the intervention need to be made with caution.

4.1 Yes the project team acknowledges this and the final report and evaluation refer to this.

5. Cancer survivors participating in the project demonstrated a high level of need for rehabilitation and community services with a total of 100 referrals instigated. Overall, 47% of participants received referrals to allied health and community services indicating a considerable unmet need for these services. To what extent were these rehabilitation needs cancer related, or associated with other pre-existing/co-morbid conditions?

5.1 A review of referrals finds that of the 46 patients receiving referrals, only 5 referrals were as a result of pre-existing conditions (eg chronic back pain, pulmonary airways disease due to lifelong smoking) All other referrals were directly related to cancer or cancer treatment (e.g. fatigue, pain, cancer distress, diet and weight loss/gain, smoking cessation, retraining and return to work,
financial, sexual counselling). Interestingly the referrals were widely spread across professional groups and across the Geelong area and Barwon region and did not result in longer waiting lists for services (as initially suggested they might). Please also breakdown of types of referrals in Peer Review response number 12.)

6. The cost assessment demonstrates the Nurse Led Survivorship Clinic does not appear to incur many resources costs, with the main costs being attributed to Survivorship Nurse salaries. Some discussion of other potential costs would be useful.

6.1 Other costs included training and education, office workspace, computer, access to electronic records, mobile phone, access to private and confidential interview rooms, appointment booking support, small amount of administration support and IT support (essential).

7. The authors note the challenges with definitions of shared care. The definition of Shared cancer care’ in this project (the GP completing some or all of the tests, scans and physical examinations previously completed by the cancer specialist or commencing these at an earlier time) could be seen to be limited to surveillance issues only. Is this what was intended and is this recommended for the future?

7.1 The project team were interested to explore and clarify the term ‘shared care’ raised in the specific requirements of the Victorian survivorship projects. 

- GPs and cancer specialists (plus other key parties) demonstrated very varying understandings and applications of this phrase.
- Perhaps the addition of the word management (e.g. ‘surveillance and management’) assists to clarify the GPs role. The project definition could be updated to
  - ‘The project definition of ‘shared cancer care’ describes the GP completing surveillance for cancer recurrence, and surveillance and management of long term treatment side effects including new cancers.
  - In practice this entails the GP conducting some or all of the tests, scans and physical examinations previously completed by the cancer specialist in outpatient review appointments, or commencing these at an earlier time in the patients post treatment care.
  - The GP is asked to conduct recommended health checks (e.g. bone scans), immunisations and psychosocial review of the survivor integrated with their ongoing primary care services to the patient.”

The authors suggest there is also a need to define and clarify the word ‘surveillance’ as varying applications have been observed.

8. The implementation of a separate clinic for high risk survivors (of a range of cancer types) was considered and not progressed on the basis that it was not consistent with tumour stream care. Were there any gaps identified for patients given that this service was not implemented? How were ‘high risk survivors’ managed in the absence of this service?

8.1 Were there any gaps identified for patients given that this service was not implemented?
- This was not formally evaluated and in general there is very limited data available about the needs of survivors (gaps) in the region (regardless of level of risk).
- Anecdotal evidence suggests that increasingly busy review clinics do impact on the time provided to high risk patients and there is certainly evidence that allied health and
rehabilitation services available to survivors attending as outpatients at Barwon Health is very limited.

8.2 How were ‘high risk survivors’ managed in the absence of this service?
- The Survivorship Nurse Led Service was offered to ‘high risk survivors’. Head and neck cancer survivors (considered to have high levels of present needs and potential to be at ‘high risk in the future’) were the second tumour group to receive the new service.
- High risk patients not referred to the survivorship service (by the cancer clinicians or staff) continued to receive the same service by attending medical review with cancer specialists.

The authors draw attention to reference number 21 (Final Report) that raises important questions about identifying and responding to patient’s ‘needs’ or ‘future needs’, as opposed to using the term ‘risk’ which is a measure of the likelihood of needs occurring in the future.

9. General health assessment tools and resources were tailored to provide survivorship specific tools and guidelines. A recommendation was made for the development of specific risk assessment tools. What are the limits of existing tools that mean this is necessary?

9.1 No existing tools could be obtained, although references in international research and survivorship projects indicated they may exist.

9.2 Definitions of “risk of what” were also limited and difficult to find.

10. A major challenge to the service is the length of time required to complete individual patient centred care plans. Up to 5 hours per patient is required to complete 2 face to face appointments, summarise treatment history, contact the GP, complete the care plan and identify resources and complete referrals. Did this improve over time? Are there any areas for efficiencies to be made?

10.1 Did this improve over time?
Initial care plans took longer than 5 hours to develop. As electronic documents were trialled and modified, referral networks developed and specialists support for the service developed the average timer to complete a survivorship nurse intervention and care plan was still considered to be 5 hours

10.2 Are there any areas for efficiencies to be made?
- Further development of electronic records capability (e.g. to self-populate treatment summaries)
- Conducting group sessions for patients completing treatment which cover all general survivorship health education (e.g. addressing fatigue, cancer recurrence, diet, exercise) would avoid the survivorship nurse repeating these messages in each individual survivorship appointment. This group health education could be followed by shorter individual consultations by the survivorship nurse to provide the other survivorship service components (e.g. individual care plan, engagement of GP, treatment summary, individual referrals)
11. Readiness to participate appears to be a key issue. Do the authors have any suggestions for how to assess readiness, and how to enable flexibility in their pathway?

11.1 Yes
- Ask the patient if they are ready?
- Repeat the invitation across time, as survivors may not ‘hear’ the first time.
- Ask team members who are already familiar with patient?
- Ensure survivorship services are available across a range of post treatment time frames
- Spread the message and repeat the message that survivorship is available i.e. avoid a once only opportunity or referral point.
- Ensure all cancer staff are familiar with and can discuss the survivorship service with patients i.e. not only cancer specialists
- Position survivorship services as a regular part of ‘after care’
- Provide survivors/carers with information and phone numbers so they can make an appointment later when they are ready.

12. The authors state that the survivorship nurse is a specialised role. Please justify and provide some description of the types of skills and abilities required by the nurse and what this means for recruitment and training.

12.1 A position description for the ongoing survivorship nurse consultant will be available shortly. Essential key selection criteria may include
- At least three years oncology nursing experience and demonstrated knowledge of cancer nursing practice
- Ability to work independently and with a high level of autonomy
- Ability to work effectively in a multidisciplinary team and demonstrate leadership skills
- A clear understanding of the underpinning philosophy of provision of survivorship care.
- A commitment to ongoing professional development and training related to survivorship
- Experience in delivering evidence-based patient education including a focus on patient centred and patient empowerment models of practice.
- Experience in delivery of group health education
- Demonstrate experience and knowledge in service development and change management
- Ability to work collaboratively with a range of health care providers and represent the cancer service and survivorship team.

12.2 What does this means for recruitment and training?
- Clear identification of skills/knowledge required and accurate recruitment
- Opportunity for training must be included in employment conditions including adequate time for research, self-directed learning( in the absence of availability of formal survivorship training), attendance at conferences and forums
- Peer mentoring and continuation of the Community of Practice are also highly supported
- The project report recommended that given the recent emergence of survivorship in cancer care delivery, engagement of health care educators and inclusion of survivorship units in health care courses should be a key priority.
13. Would the authors make any changes to their tools on the basis of their experience with the project?

13.1 Tools were trialled and upgraded considerably at in the early stages of the project. Minor changes and improvements continue in content and presentation, however the basic tools appear to remain applicable and well accepted by survivors, cancer staff, GPs and consumers.

The approach of developing document templates that can be tailored to each tumour stream continues to work well and facilitates service growth across new tumour streams.
Review of Pilot Project Final Report – Barwon South West Region

Peer Review- Document 2. Peer review comments in black font, and authors’ replies blue.

1. It requires a short description of what a survivor is and what survivorship programme you are piloting right at the start of the prior to the key messages. For someone not familiar with this area this isn’t addressed until page 7. Would work better if second paragraph (and maybe also the 3rd of page 7) were moved to the front of the report.

The authors understood the key messages were not to include a program description and were required be completed in one page. This can be modified if it is required in the future.

2. Key messages and Key Outcomes: May benefit from providing more facts about the history behind the NLSCs: what time period implemented, how many involved, classification of 3 sites; all ideally in the one paragraph.

3. I would like to know right from the start how many patients participated in the programme and actual figures (as well as the %) for adherence, responses etc. The same for GPs and other health professionals. The % without the figures is not very helpful, and likewise numbers returning questionnaires without a denominator.

4. Reducing risk. The authors don’t clearly define what risk they are talking about - it isn’t really clear until you see the figure on page X. Para 5 page 5 requires greater clarity.

Similarly the executive summary (point 4) was limited to 3 pages although it is agreed that any description and discussion of ‘risk’ is problematic and requires explanation.

5. Project Background – Regional population factors: perhaps when describing the low health literacy, mention how this can directly negatively impact the patients’ course of survivorship in terms of awareness, health promotion and lifestyle.

5.1 Agreed, however the report page limit required the pruning of this type of elaboration

5.2 ‘Survivorship champions’ in this report is a term used to describe cancer specialists (cancer doctors, haematologists, oncologists) as well as health professionals, consumers and others who:
- Demonstrated an openness and willingness to discuss impacts of cancer and treatments on survivors
- Listened to and discuss the proposed service delivery model
- Contributed to service design and delivery
- Referred patients to the service

6. Project background – Patient needs: “Current follow up and review of cancer survivors is highly focused on surveillance for recurrence of cancer. Assistance with physical, psychological, sexual and other health needs is ad hoc and relies on patients seeking information and asking questions, which they often feel unable to do.” This is a contentious area, but who exactly should look after specific chronic diseases/comorbidities that may not be necessarily due to the cancer/treatments? (My understanding is that in this scenario, the GP/specialists already involved should continue to take the reins. As you have mentioned in the ‘Cancer Specialists’
Needs section: “Discussion with cancer specialists indicated that a number of patients return unnecessarily to the hospital setting for routine tests that could potentially be followed up in the community by their GP.” So yes, current follow up should be focused on surveillance for recurrence of cancer + management of direct complications of the cancer treatments and this should be stipulated in the purpose of the Survivorship project.)

6.1 The comment in the Project Background – page 8 (as highlighted in brown above) refers to a description of current follow up of patients at the project site only and refers to patient needs as related to cancer survivorship and not to other diseases/co-morbidities. The authors acknowledge that this could have been more clearly stated.


7.1 Again the comments relating to GPs, were specific to background of the project sites. The reference appears useful however the page limitation of the project report (Department of Health specified) prevented further literature being included.

8. Survivorship Project Model Aim and Structure – Target Population:
   - Specifically mention all tumour types included and how many cases per stream
   - Define “high, medium and low risk survivors”

8.1 Specifically mention all tumour types included – Please see Aim 1 (page 9) which states the aim was to develop a service for survivors with a range of tumour types.

8.2 Number of cases per stream was not an aim of the project but emerged in the evaluation methodology

8.3 Define “high, medium and low risk survivors” A definition of these terms was not developed at the time the project aims and structure was developed. Research and discussion re the definition of ‘levels of risk’ continued throughout the project and continued to be largely undefined and remained problematic. The authors acknowledge that a statement to this effect could have informed the reader.

9. Survivorship Project Model Aim and Structure - Project implementation: “All resources were reviewed and/or trialled with consumers and clinicians prior to being piloted.” – elaborate on how this was done and how the resources were evaluated.

9.1 Resources, tools and documents
   - Were circulated for review (to be read by and feedback provided by) consumers, cancer clinicians (doctors), cancer staff, GPs, GP practice nurses and other key parties.
   - Were trialed using role play and real patient case examples to check applicability and suitability.
   - Trialed in a small ‘trial of the trail’ with actual survivors to identify any modifications required.
- Outcomes such as doctors failing to use a new referral slip indicated poor uptake and a different approach proved more successful.
- Resources were also compared and contrasted to similar documents being developed by the other Victorian Survivorship Projects.

10. Objective 3 – Key Learnings: How do you propose to prehabilitate patients?

10.1 This was a key learning and in the view of the authors a service proposal was not required.

11. Objective 5 – Risk Equation: Does risk of mental illness tie in with risk of ‘chronic disease’ ‘holistic needs’ and ‘ability to self-manage’? Because I would imagine that ‘chronic disease’ also includes bone and CV health, ‘holistic needs’ is an all-encompassing term and ‘ability to self-manage’ also includes managing schedules, fitness, literacy, budgets and fiscal restraints. The patient risk for developing mental disorders secondary to cancer/its treatment (eg pathological anxiety and Fear of Cancer Recurrence) I believe should get a special mention.

11.1 The authors agree that mental health/illness is another factor that can both be included as a holistic need, co-morbidity and chronic disease outcome. It is noted that this could be included in any future diagram illustrating the complexity of determining ‘individual risk’ guiding follow up care services.

12. Referrals to allied health: would be helpful to know what the breakdown of these were. Is it a few patients with multiple referrals or spread out – and to whom are they being referred.

12.1 (as per point 5 in Peer Review Document 1) A review of referrals finds that of 46 patients receiving referrals, only 5 referrals were as a result of pre-existing conditions (eg chronic back pain, pulmonary airways disease due to lifelong smoking) All other referrals were directly related to cancer or cancer treatment (e.g. fatigue, pain, cancer distress, diet and weight loss/gain, smoking cessation, retraining and return to work, financial, sexual counselling, hearing loss). Interestingly the referrals were widely spread across professional groups and across the Geelong area and Barwon region and did not appear to impact on existing waiting lists for services (as initially anticipated). The greatest number of referrals were related to exercise assessment and reconditioning (12 physiotherapy or exercise physiology referrals), smoking cessation (8) and social work (4).

13. Length of time of consultations in the Nurse Led Survivorship Clinic?

14. Next steps for the program - Development of shared care and transition pathways from Cancer Centre to Primary Care:

15. These should ideally be developed on a common template, employable at all sites (rural or urban).

Comments 13 to 15 were not clear in any requests for information or clarification.

The authors have had appropriate consumer and stakeholder input at each stage of the model. This has been in the form of qualitative interviews as well as questionnaires as well as having consumer input into the actual design of the model. Possibly further quantitative information on the needs of survivors within their specific area could have been obtained prior to establishing the
programme. The development of survivorship care plans is appropriate and supported by guidelines from the major international oncology societies. They have also determined from GPs what information they would like. The model has included work force training programmes

They have addressed the applicability and spread of the model and provided sufficient detail to support establishing the same model for other tumour types or at other clinical sites. This has been assisted by an outline of enablers and challenges for each of the major objectives.

The model is relatively inexpensive and has been set up and run with minimal resources, by utilising existing resources wherever possible. An economic analysis has been included to outline costs. The team have determined co-ordinated referral pathways and clearly outline potential challenges to these. Increasing use of primary care practitioners to provide longer term follow up has the potential to lead to significant cost and resource saving providing it is done well. Impact of the model on patients and staff has been substantial – as supported by the qualitative comments from survivors and health professionals throughout the report, and by ongoing referrals to the Survivorship Clinic after the project finished.

I am not convinced that ‘high risk’ survivors necessarily require more multidisciplinary input than those at lower risk of a cancer recurrence. In my opinion long term side effects from treatment, psychosocial issues obesity, lack of exercise and lack of social supports are possibly more likely to determine morbidity rather than staging of original disease.

This is a really good comment to illustrate that the definition of ‘high risk’ is very varied and problematic. In this case the peer reviewer appears to have defined risk as being related to ‘staging of the original disease’. The authors have found that ‘risk’ is defined and applied in a variety of ways across different health and professional contexts e.g.

- Risk of recurrence?
- Risk of late and long term treatment effects arising?
- Risk of new cancers arising?
- Risk of chronic disease related to treatment, or due co-morbidities?
- Risk of distress and mental illness?
- Risk of high service needs/demand?
- Risk of isolation and lack of access to follow up services?
- Medical risk or non-medical risk?
- Risk of falling through the service gap between the cancer centre and the GP?

Finally – the logo is great. Congratulations on your well thought out feasible model.

Are some minor typos. – OOPs we agree!

Many thanks