# Supporting cancer survivors in Victoria

Learning from the Victorian Cancer Survivorship Program pilot projects

2011–2014







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# **Foreword**

Preparing cancer survivors for life after cancer should be an integral part of providing care. With increasing numbers of survivors and improved understanding of the range of challenges experienced post-treatment, new approaches are required. Current models of care are ill-equipped to cater for these demands. What is urgently needed is best-evidence guidance on medical follow-up and holistic interventions to support improved quality of life.

We established the Victorian Cancer Survivorship Program (VCSP) in 2011 to 'develop innovative models of follow-up care' for addressing the needs of survivors post-treatment (Department of Health 2008, p. 47). We piloted a range of approaches: shared care and discharge to GP follow-up; a survivorship pathway for adolescent and young adult survivors; and interventions to support self-management and improved physical activity and nutrition.

Much has been learned about the varied needs of survivors and enablers and challenges for implementing survivorship care in Victoria. Systems are needed to deliver needs assessments, self-management support and improved care coordination. Survivors can benefit from rehabilitation and chronic disease management approaches. Partnering with primary care, cancer-related non-government organisations and other community-based organisations can extend the reach of tailored survivorship support.

This report shares the lessons we learned through the VCSP projects. I would encourage you to consider its content and recommendations when designing and implementing survivorship programs. Addressing the needs of increasing numbers of survivors will require creative approaches. By working together, we can reduce the impact of cancer and chart a course to improved health and wellbeing for survivors.

Professor Robert Thomas

**Chief Advisor for Cancer** 

# Case study

The target audiences for this report are policymakers, health service managers, health professionals, cancer-related non-government organisations, primary care organisations and interested consumers.

The following case study illustrates the positive benefits of addressing the longer term effects of cancer treatment through survivorship programs.

'I was a fit, healthy 47-year-old travelling overseas in 2006 when I was diagnosed with acute myeloid leukaemia. There followed a range of emotions that encompassed shock, horror and a fairly healthy slab of determination. That determination was to be tested early when I failed chemotherapy ... and I was faced with an allogeneic stem cell transplant. Complications of this were many, but the most significant with long-term ramifications was lung damage. [I then participated in a VCSP project.]

In no time at all I found myself at just over 53 years of age joining a gym... for the first time... [Now] I walk on a treadmill, do ... weights, ride the stationary bike, do squats and row miles on a machine. To my surprise, I actually manage to do these things three times a week!

I can see some difference in myself. I have lost a small amount of weight, more in measurements and gained tone, but my measure is my fitness – I can now climb steps much better than I used to, but the real test is what I call "boot camp hill"... Prior to this program I could walk up this hill with four stops to breathe, then it became three stops, then two and now I don't stop at all. I celebrated that day I can tell you – the sense of achievement was amazing! My lung capacity has not improved and today sits at just under 50% of normal, but my new fitness means that I can carry myself up that hill much easier than I did before the survivorship program...

When I think of those early days post-transplant when I could hardly walk the length of my house to get to the letterbox compared to the person I am today – I owe much to the Positive Change for Life program!'

Positive Change for Life program participant

# Acknowledgements

The writers acknowledge:

- the Victorian Department of Health & Human Services for funding and driving policy to test innovative models of survivorship care
- the Australian Cancer Survivorship Centre
- the VCSP steering committee and project teams
- the Australian Health Workforce Institute, University of Melbourne
- the VCSP Community of Practice
- Victorian Integrated Cancer Services
- Networking Health in Victoria (formerly known as General Practice Victoria).



# Background

Sustainable models of follow-up care are required to meet the needs of increasing numbers of cancer survivors. There are an estimated 230,000 cancer survivors living in Victoria (Cancer Council Victoria 2014). Survivors report a range of physical, psychological, emotional and practical challenges following cancer; and some also experience other chronic health conditions (Macmillan Cancer Support 2014). New approaches to 'survivorship' care need to address medical follow-up, chronic disease impacts and quality of life.

The Victorian Cancer Survivorship Program (VCSP) was initiated in 2011 to pilot new models of survivorship care within the Victorian health system. The program aimed to trial collaborative models of care across acute and primary/community care sectors and to evaluate these interventions for their effectiveness, acceptability, sustainability, transferability and ability to facilitate survivor involvement and self-management. It sought to improve our understanding of the specific survivorship care needs of different groups, develop resources tailored to survivors' and health professionals' needs and inform future survivorship care in Victoria.

# The VCSP pilot projects

The VCSP funded six projects to pilot different models of care across a range of settings and survivor populations. The six projects were:

- Survivorship program for patients completing definitive breast cancer treatment.
- Barwon South West Survivorship Project: Improving outcomes for survivors of cancer.
- Melanoma Shared Care: A tripartite approach for survival, the patient, their GP and their specialist.
- Survivorship Connections: A model of youth-friendly survivorship care.
- Moving Forward With Confidence: Increasing the capacity for self-management in cancer survivors.
- Positive Change For Life: Improving health, wellbeing and quality of life for survivors of blood cancer following stem cell transplantation by promoting a healthy lifestyle through diet and physical activity.

The projects worked across a range of settings and survivor populations. Most projects recruited survivors within 12 months of the end of their treatment for early stage cancer.

- All projects developed survivorship care plans (SCPs).
- All projects sought to engage general practitioners (GPs) in collaborative survivorship care, although the specific role of GPs in follow-up varied. These roles ranged from GP follow-up care of survivors assessed as 'low risk', to follow-up alternating between specialists and GPs.
- Three projects provided routine specialist follow-up but sought to engage GPs and other partners such as cancer-related non-government organisations (NGOs) and community fitness centres in collaborative health and wellbeing promotion, self-management and chronic disease management and surveillance approaches.

# Outcomes, lessons, challenges and enablers

Variability of project design poses challenges for evaluation and limits comparison and the ability to establish causal relationships between interventions and outcomes. Individual project evaluations were impacted by issues that included delays in obtaining ethics approval and recruitment challenges. These issues impacted on the ability to demonstrate robust outcomes within project timeframes. This report identifies common outcomes and lessons, enablers and challenges for implementing survivorship care in Victoria under themed headings.

#### Needs assessments

Four of the six projects conducted needs assessments to inform care coordination and SCP development. Screening tools were commonly used to identify supportive care needs, symptom impact/management and quality of life, although approaches varied. Some projects used needs assessment findings to inform risk stratification. Most acknowledged that needs change over time and repeat assessment may be required. Patient-reported outcome measures were used to measure project outcomes.

# Survivorship care plans

SCPs were positively received and viewed as a valuable communication tool by survivors, hospital staff and GPs. GPs were more likely to discuss SCPs with participants within a model of shared care. Information presented in chronic disease management terms helped 'translate' the SCP for GPs and supported preparation of Medicare chronic disease management plans and team care arrangements (Australian Government Department of Health 2014). Sustaining time-consuming SCP interventions within existing resources presented challenges for some projects.

## Risk-stratified pathways

Risk-stratified pathways for transitioning to shared care with a GP or discharge to GP follow-up were successfully piloted across breast, melanoma and haematology tumour groups. Where evidence to guide stratification was limited, cancer specialists assessed risk on an individual basis. Supportive care needs, disease and treatment factors informed risk stratification. All pathways incorporated processes for rapid re-access to specialist care.

### Health literacy

Two projects measured health literacy and health education impact. Both reported high baseline function and positive shifts for some domains of health literacy and health education impact.

#### Models of care

# a. Shared care with GPs or discharge to GP follow-up and engagement with primary care

High levels of acceptability and satisfaction with shared care/discharge to GP follow-up were reported by the three projects piloting this model. Due to time constraints, system and health service outcomes were limited, although one project completed preliminary modelling that indicated one to two fewer hospital follow-up appointments per year, freeing up capacity.

GP engagement presented challenges across the projects. Most projects included primary care representative organisations on their steering committees. Opt-out approaches to obtaining GP consent to participate in shared care/GP follow-up facilitated implementation.

#### b. Nurse-led clinics and care coordination approaches

Two of the six projects established nurse-led clinics (NLCs) following active treatment. Two projects provided allied health and nursing care coordination interventions (although not in an NLC). NLCs facilitated supportive care screening, tailored information provision, linkage with services and transition to GP follow-up. Risk-stratified telephone-delivered interventions were acceptable to survivors. The projects did not compare the efficacy of NLCs with other models of care.

#### c. Partnerships with community-based organisations

Most projects worked closely with community-based organisations as either project partners or in a consultative role. Community-based organisations like fitness centres and the Cancer Council Victoria helpline service provided health promotion and self-management support interventions for survivors.

# Impact on survivor self-management

Two of the six projects delivered longer term self-management support interventions incorporating motivational interviewing or coach for heart health models. One project assisted survivors to self-manage their diet and physical activity levels. Outcomes included increased physical activity levels, improved nutrition, weight loss, reduced fatigue and enhanced quality of life.

#### Carer outcomes

Although projects did not specifically target carers' needs, some projects invited participants to include carers in consultations, albeit with limited uptake. One project noted that carers played a significant role in supporting health promotion and wellbeing. The adolescent and young adult (AYA) project highlighted that AYA carers have significant unmet needs.

#### Workforce education

Workforce education was considered key to implementing and sustaining new models of care. A range of survivorship educational activities were provided for health professionals including, GPs and primary health care nurses as well as those working for acute services, cancer-related NGOs and community fitness centres.

# Economic evaluation and sustainability

The shared care/discharge to GP follow-up projects hypothesised a cost shift from acute to primary care and improved access to outpatient clinics for new patients but did not build in specific evaluation of this. More evidence is required to predict sustainability for some aspects of project interventions. The shared care/discharge to GP projects have the potential to deliver sustainable models of follow-up care. A partnership with the Leukaemia Foundation is enabling ongoing delivery of a physical activity and nutrition program and a specialist AYA service supports ongoing survivorship care planning for AYA survivors.

# Workforce evaluation

The Australian Health Workforce Unit, University of Melbourne, completed an overarching workforce evaluation; its key recommendations for policy, practice and research are included in this full report.

#### **VCSP** recommendations

- Develop information technology (IT) solutions to identify survivors at the end of their treatment and populate treatment summaries.
- Prepare survivors early for potential longer term effects of cancer and its treatments and medical follow-up arrangements.
- Improve access to needs assessment and care coordination following treatment. Develop
  validated tools and consider conducting needs assessment at the end of treatment in the context
  of Victorian supportive care policy.
- Support self-management during and after cancer treatment. Promote the importance of healthy lifestyle behaviours and actively participating in medical follow-up.
- Strengthening linkages between acute cancer services and cancer-related NGOs can improve timely access to information and support.
- Extend and promote education for health professionals about survivorship needs, evidence-based interventions and the contribution of a range of services to survivorship care.
- Shared care/discharge to GP follow-up models appear to be acceptable to low-risk cancer survivors. Further work is needed to:
  - build sustainable models of shared care
  - develop evidence to establish risk stratification guidelines
  - o evaluate the economic and longer term impacts of these models on survivor outcomes.
- Risk stratification approaches are required to target interventions. A range of interventions
  and delivery mechanisms need to be considered to meet the needs of heterogeneous groups
  of survivors.
- To help implement survivorship initiatives, consider policy development, clinical leadership, redesign programs and change management approaches, as well as infrastructure and engagement strategies.

# Conclusion

Implementing survivorship care in Victoria is a work in progress. Extended timeframes are required to embed new models and roles. Aligning cancer with chronic disease management models and conceptualising future projects in primary care may facilitate engagement. Supporting survivors to self-manage and partnering with community organisations could help services to more flexibly cater for the needs of increasing numbers of survivors. Considering the enablers and challenges identified in this report will help when implementing future survivorship initiatives.



# Organisation/system

- Strong clinical leadership and project management principles are critical for effective implementation.
- Developing a strong business case is important before implementing new models of care.
- Information management systems can support or impede the identification of patients at the end of their treatment. They can also help generate SCPs and improve communication with general practice.
- Establish shared understandings of terminology (survivor, nurse-led clinic/service, shared care).
- Flexible models and interventions are needed to meet the needs of diverse groups of survivors and various healthcare settings.
- Strong consumer engagement is needed to tailor models, interventions and tools.
- It is important to consider principles of service and workforce design when initiating new models
  of care. Reorientating health services to support self-management and wellness requires major
  cultural change.

# Engaging primary care

- Most GPs are willing to provide cancer surveillance for low-risk survivors.
- Establishing and communicating clear roles and responsibilities in survivorship care is essential.
- If formal agreements of transfer of care are used, opt-out processes are easier to implement.
- Align survivorship with chronic disease management frameworks and GP working models/ processes.

### Community partnerships

- Strengthening referral pathways between health services and cancer-related NGOs improves access to survivorship support. NGOs are seeking to partner with health services in survivorship care.
- Cancer-related NGOs can be well placed to deliver self-management support.
- Improving access to rehabilitation and allied health interventions could better support survivor self-management; cross-sector education about survivorship is required.
- Community fitness centres can be supported to deliver physical activity programs to survivors.

#### Intervention components

- Capacity to complete needs assessments and risk stratification is critical for tailoring care.
- Improved understanding of how needs assessment findings interrelate with risk stratification criteria assists when developing risk-stratified pathways.
- There are a lack of supportive care screening and prediction tools validated for use post-treatment.
- Selecting appropriate, sensitive outcome measures to evaluate multifaceted interventions is challenging.

# Survivors

- Some individuals and some cultural groups do not identify with the terms 'survivor' or 'survivorship'; some prefer terms like 'recovery'.
- Survivors valued the opportunity to discuss their supportive care needs following treatment.
- Individual readiness to engage with survivorship planning varies.
- It is important to prepare survivors during treatment for the potential impacts of cancer and how/ where to access assistance following the treatment phase.
- Empowering survivors to seek post-treatment information and support is important.
- Preparing survivors early for GP follow-up helps them to accept shared care.



# 1.1 Victorian Cancer Survivorship Program (VCSP)

In 2011, the Victorian Department of Health & Human Services (formerly the Department of Health) sought applications from acute and community health services under the Victorian Cancer Survivorship Program (VCSP) pilot project grant scheme to develop and pilot sustainable models of cancer survivorship care. In this context survivorship is defined as 'the phase of care that follows primary treatment for cancer' (Hewitt, Greenfield & Stovall 2006, p.2). Innovative models were required to coordinate and link specialist cancer teams with primary and community providers and/or non-government organisations (NGOs) and develop patient-centred approaches to survivorship care. Following expert panel review, six pilot projects were granted funding for a two-year period. A six-month extension was later granted in response to delays in securing ethics approval.

The projects worked to improve health outcomes for survivors following hospital-based treatment. They aimed to develop and implement different models of care for different patient populations within different contexts. This approach sought to test and identify the strategies and variables that foster and facilitate good survivorship care for specific groups in the Victorian health system.

The projects did not share an overarching evaluation framework; however, common lessons, enablers and challenges for implementing models of survivorship care were reported. This report highlights these key factors that impact on the implementation of survivorship care.

The report draws upon the experiences of the pilot projects to discuss the following:

- needs assessment
- survivorship care plans (SCPs)
- risk-stratified pathways
- models of care
- survivor-reported outcomes
- · impacts on health literacy, self-management capacity and healthy lifestyle behaviours
- carer outcomes
- partnerships with primary care
- sustainability considerations
- characteristics of the models that may be relevant for future implementation or policy.

For more information about the VCSP selection process and pilot project application guidelines refer to Appendices 1 and 2.

# 1.2 Background

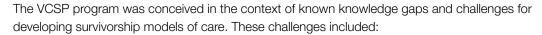
The VCSP was initiated in response to a number of identified drivers:

a. Improvements in cancer screening and treatment coupled with ageing populations are creating a growing population of cancer survivors. Approximately 230,000 survivors live in Victoria (Cancer Council Victoria 2014). Victoria accounts for 24.9% of the Australian population (Australian Bureau of Statistics 2014). Therefore it could be estimated that there are at least 900,000 survivors in Australia. There are large groups of breast, prostate, melanoma and bowel cancer survivors among this number (Cancer Council Victoria 2014). A Cancer Council Victoria media release in 2014 announced that average Victorian five-year survival rates had risen to 66%. Average 2006–2010 survival rates for adolescent and young adult (AYA) survivors are reported as 87% (Thursfield et al. 2012). Many survivors will live many years following cancer treatment.

Factors further compounding the challenge of catering for the growing number of people affected by cancer include:

- Nearly half (45%) of Victorian survivors are over 70 years of age (Cancer Council Victoria 2014).
- It is estimated that cancer incidence will increase by 53% by 2023–2027 (Thursfield et al. 2013). Continuing to provide traditional models of outpatient follow-up to all survivors will not be sustainable and may not meet the needs of all survivors.
- b. While most survivors report good quality of life post-treatment, for many, both the experience of cancer and cancer treatments greatly affect their general health outcomes and quality of life. The range of physical, psychological, emotional and practical challenges that many survivors experience following cancer are well documented (Macmillan Cancer Support 2012). For some, long-term and late effects of treatments result in significant burden of disease and an increased risk of other chronic health conditions. Many survivors are also managing pre-existing chronic health conditions.
- c. Consumers report needing greater preparation for what to expect following treatment; some report unmet needs and experience a sense of abandonment at the end of treatment. Lack of acknowledgement of common survivorship challenges and access to needs assessment and care coordination at the end of treatment leaves some survivors poorly prepared for life after cancer.
- d. Growing awareness of the long-term and late effects of cancer has given rise to increasing research to support the development of evidence-based guidelines for preventing and managing these effects. Despite the development of consensus-based guidelines for the long-term care of cancer survivors in the United States and United Kingdom (UK), the implementation of survivorship care is in its infancy in Victoria. Oeffinger and McCabe (2006) note that, from an American perspective, new models need to be developed that are sustainable, cost-effective, clinically-relevant and deliver health and quality of life of benefits to cancer survivors. Models need to incorporate agreed principles of aftercare and consider the local healthcare setting (Jefford et al. 2013).

For more background information from the literature refer to Appendix 3.



- developing new models/interventions in the absence of clear guidelines
- · limited evidence regarding alternative models of care
- limited existing models for transitioning care between sectors
- identifying who benefits most from which type of intervention
- understanding the different needs of different groups
- developing models of care that are responsive to individual needs
- organisational cultural barriers such as the traditional specialist model of cancer patient follow-up
- redefining/ expanding work force role
- survivor readiness to accept new models of follow-up
- limited healthcare resources.

# 1.3 VCSP objectives and principles

# **Objectives**

- Pilot cancer survivorship post-treatment shared models of care across the acute and primary care sectors accessing existing services and funding streams (for example, Medicare Benefits Scheme chronic disease management items).
- Evaluate cancer survivorship models/interventions in terms of their effectiveness, sustainability and transferability across settings.
- Develop resources (for both patients and service providers) and recommendations for future improvements in follow-up care.
- Improve understanding of the specific survivorship care needs of different groupings.
- Facilitate cancer survivor involvement and self-management.

#### **Principles**

- Follow-up care is tailored to meet individual needs and considers diverse population groups.
- Care will be delivered in the community and/or there will be strong engagement with the community sector.
- Models of care will demonstrate strong consumer engagement.
- Survivors will be linked with existing services and 'packages of care' tailored to individual needs (physical, psychological and social needs).
- Specialist cancer clinicians, primary care providers, nurses and allied health providers are engaged in a formalised transition pathway, from acute to community care settings, and vice versa.
- Self-management strategies for survivors and their families/carers and peer support opportunities
  are included as a component of follow-up care.
- Care is coordinated through timely and effective communication:
  - tele-health
  - web technologies (such as internet and video linkage)
  - face-to-face consultations.

# 2. The VCSP pilot projects

The six VCSP projects piloted different models of care across a range of different settings, with varied populations of survivors. All projects were supported by:

- a state-wide survivorship community of practice that met regularly to share ideas and problem solve project challenges
- the Australian Cancer Survivorship Centre
- the shared survivorship workspace hosted on the Hume Regional Integrated Cancer Service website.

All projects were conceptualised in acute health services regardless of the model or care setting. All developed SCPs and sought to engage GPs in collaborative survivorship care; however, the role of GPs in follow-up varied across the projects. Some projects transferred the follow-up care of survivors assessed as 'low risk' to general practice for ongoing management and some alternated follow-up between specialists and GPs. Others continued to provide routine specialist follow-up but sought to engage general practice in collaborative health and wellbeing promotion, chronic disease management and surveillance approaches.

The projects were funded to support survivors at the end of treatment for early cancer and were not tested with those with advanced cancer.

Common deliverables were specified in the grant application and the projects developed evaluation methodologies with their specific population and model of care in mind. The absence of a shared evaluation framework and control groups across the projects precludes inter-project comparison of interventions and limits the ability to establish causal relationships between interventions and outcomes. This report highlights patient-reported outcomes and health professional responses to the models of care. The department commissioned the Australian Health Workforce Unit, University of Melbourne, to complete an overarching workforce evaluation. Key recommendations from this evaluation are also included in this report (Appendix 10).

# 2.1 Outline of individual projects

The VCSP application guidelines specified targeting survivors at the end of their treatment, and most projects recruited survivors at less than 12 months following the end of treatment. Readiness of survivors and cancer specialists to engage with survivorship interventions/models of care impacted on the timing of interventions across some projects. Full project reports for each VCSP pilot project are available through the Australian Cancer Survivorship Centre.

# 2.1.1 Breast Cancer project

Survivorship program for patients completing definitive breast cancer treatment

#### Target population

Survivors who have completed definitive treatment for early breast cancer

#### **Objectives**

- Develop, implement and evaluate a model of survivorship care for women with low-risk breast cancer.
- Improve quality of care at the end of treatment.
- Reduce the intensity of hospital-based care and create greater capacity for new patients.

#### Intervention

Survivors with early breast cancer including ductal carcinoma in situ were risk stratified to shared care follow-up with GPs at the multidisciplinary meeting (MDM). Risk stratification considered disease, social and psychological factors. Eligible survivors were offered a face-to-face or telephone-delivered nurse-led clinic (NLC) consultation designed to:

- · review disease, pathology, treatment and follow-up requirements
- discuss psychosocial, physical and treatment-related concerns
- refer to health professionals and support networks
- develop SCPs.

SCPs were approved by a breast service cancer specialist. Nurses facilitated shared care arrangements with a GP nominated by the survivor. The outcomes and impacts of NLCs and shared care were evaluated with survivors and health professionals.

# **Delivery sites**

The Royal Women's Hospital, The Royal Melbourne Hospital, Footscray Hospital

#### **Project partners**

The Royal Melbourne Hospital, The Royal Women's Hospital, Western Health, BreaCan, Inner North West Melbourne Medicare Local

# 2.1.2 Barwon South West Survivorship Project

# Barwon South West Survivorship Project: Improving outcomes for survivors of cancer

# **Target population**

 Survivors aged over 18 years living in regional and rural areas who have completed treatment within the last two years

# **Objectives**

- Develop nurse-led survivorship services in a regional and rural area.
- Develop individual SCPs for patients with a range of cancer types.
- Coordinate pathways of care between cancer services, primary care and allied health providers.
- Address the needs of low- and high-risk survivors.

# Intervention

SCPs and one-page tumour-specific surveillance schedules for GPs were developed for eight types of cancer. Nurse-led services were created across three sites. Participants accessed two appointments with the survivorship nurse, scheduled a week apart. A survivorship nurse provided cancer specialist-approved SCPs, health education, supportive care screening and care coordination and assisted with the transition to shared care with nominated GPs for eligible survivors. A model of care that transitions survivorship care from cancer services to primary care was developed. Quality of life, health literacy, health education impact, cost and satisfaction (health professionals and survivors) were evaluated.

# **Delivery sites**

Barwon Health (Geelong), Western District Health Service (Hamilton), Colac Area Health Service (Colac)

# **Project partners**

Barwon South Western Regional Integrated Cancer Service, Barwon Health, Western District Health Service, Colac Area Health Service, Barwon Medicare Local, Great South Coast Medicare Local, Deakin University

# 2.1.3 Melanoma project

Melanoma Shared Care: A tripartite approach for survival, the patient, their GP and their specialist

# Target population

 English-speaking patients over 18 years of age with a confirmed melanoma diagnosis attending the Victorian Melanoma Service

# **Objectives**

- Improve communication between melanoma survivors, cancer specialists and GPs.
- Improve consistency of treatment irrespective of treatment setting.
- Provide GP-delivered treatment locally where appropriate.
- Resource survivors to be informed, active participants in their ongoing surveillance.

#### Intervention

Following acute treatment, an ongoing surveillance plan was established by cancer specialists in consultation with survivors. Low-risk melanoma survivors were discharged to GP follow-up. Risk stratification was determined on an individual basis using agreed criteria. At discharge, survivors were given a diary resource containing a treatment summary and surveillance plan. Electronic reminders were generated at key time points to support survivors to better self-manage, review their supportive care needs and perform skin self-examinations. A brief discharge summary providing a comprehensive treatment history and recommendations for follow-up was provided to nominated GPs. Acceptability and satisfaction with the program was evaluated with participants and GPs.

#### **Delivery sites**

Victorian Melanoma Service, Alfred Health

#### **Project partners**

Victorian Melanoma Service (Alfred Health), Gippsland Regional Integrated Cancer Service, Southern Melbourne Integrated Cancer Service, Peninsula General Practice Network, Melanoma Patients Australia



# Survivorship Connections: A model of youth-friendly survivorship care

# **Target population**

• Victorian AYA survivors within three months of treatment completion

# **Objectives**

- Implement a model of survivorship care for AYA survivors.
- Evaluate the appropriateness, acceptability and sustainability of the model.
- Develop resources to support post-treatment AYA survivorship care and promote self-management.

#### Intervention

The project implemented developmentally appropriate supportive care screening, care coordination and regular reviews. AYA specialists supported care coordinators across sites to tailor assessments and interventions to AYA survivor needs. Care coordinator interventions were delivered alongside clinic appointments. Survivors were encouraged to engage with primary care and acute/primary care partnerships were fostered. SCPs were developed with survivors, approved by cancer specialists and sent to nominated GPs. Cancer specialists continued to provide routine cancer-related follow-up. Needs assessments, quality of life, general health and wellbeing and program acceptability and sustainability were evaluated. Carers' needs were also evaluated.

## **Delivery sites**

ONTrac at Peter Mac Victorian Adolescent and Young Adult Cancer Service, The Royal Melbourne Hospital, Bendigo Health

### **Project partners**

ONTrac at Peter Mac Victorian Adolescent and Young Adult Cancer Service, Peter MacCallum Cancer Centre, The Royal Melbourne Hospital, Bendigo Health, CanTeen Australia, The University of Melbourne, Victorian and Tasmanian Youth Cancer Advisory Board

### 2.1.5 Moving Forward with Confidence project

Moving Forward with Confidence: Increasing the capacity for self-management in cancer survivors

### **Target population**

Survivors within 12 months of the end of treatment for colorectal, breast or haematological cancer
or a variety of cancers recruited through an ambulatory oncology rehabilitation program, support
groups and the Cancer Council Victoria nurse helpline service

### **Objectives**

- Assist survivors to more independently manage their post-treatment health and optimise their sense of wellbeing in the context of their disease history.
- Build health professional awareness of common issues facing survivors.
- Educate cancer nurses to promote increased self-management abilities in their patients.

#### Intervention

Oncology nurses supported survivors to develop wellbeing-focused SCPs and the Cancer Council Victoria nurse helpline service provided follow-up telephone support with the plans three times over an eight-month period. Copies of SCPs and plan updates were provided to participants, health services, nominated GPs and the helpline service. Nurses were educated to promote survivor self-management. Health literacy, health education impact, self-efficacy, acceptability and satisfaction were evaluated.

#### **Delivery sites**

Austin Health, Eastern Health, Northern Health, Cancer Council Victoria nurse helpline service

# **Project partners**

North Eastern Melbourne Integrated Cancer Service, Austin Health, Eastern Health, Northern Health, Cancer Council Victoria, Queensland University of Technology

# 2.1.6 Positive Change for Life project

Positive Change for Life: Improving health, wellbeing and quality of life for survivors of blood cancer following stem cell transplantation by promoting a healthy lifestyle through diet and physical activity

# Target population

 Survivors of haematological cancer in ongoing remission following autologous/allogeneic stem cell transplantation, at least two years post-treatment

#### Objective

 Provide a range of community-based physical activities, support and health education opportunities to enable survivors to take an active role in their ongoing physical and emotional healing to benefit health, wellbeing and quality of life.

## Intervention

A 12-month program of individualised community-based physical activity, nutrition/dietetic support, group activities and motivational strategies was provided to eligible survivors. The Alfred Health Late Effects Clinic, the Leukaemia Foundation and other clinical haematology services referred survivors to the program. All participants received face-to-face and telephone dietetic support, a physical activity plan tailored to their needs and preferences and cost-neutral memberships to fitness centres. Participants were referred to exercise physiology if indicated. Acceptability, effectiveness, uptake, cost benefits and sustainability of the program were evaluated. The outcomes and impacts of the intervention on quality of life, fatigue, engagement in physical activity, dietary intake and a range of anthropometric and laboratory measures were reported.

# **Delivery sites**

Alfred Health, community fitness centres

#### **Project partners**

Alfred Health, Southern Melbourne Integrated Cancer Service, Leukaemia Foundation

Refer to Appendix 4 for a table outlining the VCSP pilot projects.

# 3. Outcomes, challenges and enablers

Some projects did not report definitive outcomes for selected VCSP program objectives. Project evaluations were impacted by:

- challenges obtaining ethics approval for qualitative research designs resulted in lengthy delays which affected recruitment numbers and the follow-up periods (most projects)
- difficulties identifying and capturing survivors at the end of treatment, which affected recruitment numbers (some projects)
- staff turnover within project teams, which affected recruitment and project delivery
- successful implementation of new models of care requiring pragmatic and flexible approaches; action learning approaches impacted on the ability of evaluation frameworks to demonstrate clear outcomes (some projects). Some projects did not adapt their evaluation framework in response to altered implementation plans.

At times these challenges affected the ability to demonstrate robust outcomes within the project's timeframes. Some projects have been extended to enable further data collection and/or embedding of their models (Breast Cancer project, Barwon Health project, Positive Change for Life project). ONTrac at Peter Mac is also continuing to collect data to define AYA survivorship needs.

The variability of projects poses challenges for evaluation. Where possible, this report attempts to employ a standardised approach to reporting data. Inconsistencies in reporting across the projects are reflected in the way some data is reported. Outcomes are reported for survivors, services and systems where there is data for each of these levels. In some instances, best examples across the six projects are reported. Where available, quotes from participants are included.

Project outcomes, enablers and challenges for implementation are highlighted under the following themes:

- needs assessment
- SCPs
- risk-stratified pathways
- models of care
- health literacy
- impacts on survivor self-management
- carer outcomes.

System-level outcomes, enablers and challenges are presented in terms of:

- workforce education
- economic evaluation
- sustainability
- evaluation approach.

# 4. Needs assessments

#### Key messages

- Survivor needs change and needs assessment is required at more than one point in time.
- Needs assessments facilitate timely referral processes and appropriate use of resources.
- Needs assessments assist in promoting self-management.
- There is no 'one size fits all' approach to assessment.

Using a needs assessment tool promotes consistency in assessment and guides consultation. Routinely assessing for needs assists in identifying if survivors have problems or concerns and determining their impact or urgency. This enables appropriate and timely targeting of resources to meet these needs (National Cancer Action Team 2011). It is recommended that needs assessments are conducted at key time points throughout the cancer experience and into survivorship. A 'one off' assessment is not considered sufficient (Watson et al. 2012).

Most projects incorporated self-reported measures to screen for physical, emotional, spiritual, family and practical problems. The National Comprehensive Cancer Network *Distress thermometer and problem list* (see Appendix 5) was commonly used (Brennan et al. 2012). This self-assessment screening tool is validated to identify unmet supportive care needs in people with a diagnosis of cancer before or during the cancer treatment phase. In usual practice the tool is explained to the patient and completed by them prior to a face-to-face or telephone consultation.

The Distress thermometer and problem list is not validated for use in the survivorship phase. Some of the problem list prompts highlight short-term effects of treatment that may not be appropriate in the longer term post-treatment phase. Some project teams elected to use this tool as it was already embedded in their service provision at diagnosis and during treatment, and therefore familiar to patients and health professionals. Use of a validated supportive care screening tool at diagnosis has been Victorian Government policy since 2009 (Department of Human Services 2009). Most survivor participants were screened within 12 months of the end of treatment; however, the timing of screening varied across the projects. Four out of the six projects used screening to inform the development of SCPs.

Five out of the six projects used patient reported outcome measures (PROMs). Some projects used PROMs to inform needs assessment, while others used them to measure project outcomes. Studies have shown that using targeted tools can lead to 'more patient discussion, better symptom control, increased supportive care measures and patient satisfaction' (Kotronoulas et al. 2014). Using PROMs helped identify high-risk groups, inform care plan development and prompt appropriate referrals to support self-management.

Refer to Appendices 5 and 6 for PROMS used in the pilot projects and the timing of administration.

The Breast Cancer project translated a version of the *Distress thermometer and problem list* into six languages. These documents are yet to be validated and approved for use in Victoria. *Distress thermometer and problem list* data was not reported. The project also incorporated the Menopause Rating Scale (MRS) (Schneider et al. 2000) and the Functional Assessment of Cancer Therapy – Breast (FACT-B) (Brady et al. 1997) at baseline. These tools are validated in six languages.



- The MRS identified that 28/89 (31%) participants reported not feeling satisfied with their sex life and 56/166 (34%) did not feel sexually attractive (response rate (RR) not reported).
- FACT-B identified that most (69%) women were satisfied with how they were coping with cancer; however, pain, difficulty in meeting family needs and worry about family members developing cancer were highlighted. Summarised FACT-B data is reported in Table 1.

Table 1: FACT-B data summary

FACT-B	No	%
Were satisfied with how they were coping with cancer	119/173	69
Reported pain in the previous week	108/173	62
Were content with their quality of life post-treatment	101/175	58
Were still experiencing trouble meeting the needs of their family due to their physical condition	73/173	42
Were concerned about family members developing cancer	68/177	39
Were worried about the impact of stress on their illness	65/174	37
Reported pain affected them 'quite a bit' or 'very much'	26/108	24
Indicated swelling or tenderness in one or both arms	36/174	21
Were worried about their condition worsening	33/174	19
Reported fear of death as a result of breast cancer	22/175	13

As a result of screening, 165 referrals were made during the NLC consultation. Some participants received more than one referral. Nearly all (155/165, 94%) of these referrals were accepted. Primarily referrals were made to peer support services (66), psychology/mindfulness (31) and menopause services (31). Information resources provided at the NLC pertained to exercise/nutrition (64), the physical side effects of treatment (42) and gynaecological issues/sexuality (37).

The Barwon South West Survivorship Project developed a general health assessment tool (non-validated). All 99 participants (RR 100%) completed this in combination with the *Distress thermometer and problem list*. Problems identified during screening were not reported. Following NLC consultation, 47/99 (47%) participants received referrals to allied health professionals including nutritionists, social workers, dentists, cancer support groups, sexual health counsellors, exercise physiologists and podiatrists. A total of 100 referrals to community and hospital-based services were made. All allied health professionals indicated the referrals were appropriate.

The Melanoma project relied on cancer specialist assessment as a means of supportive care screening. Copies of the *Distress thermometer and problem list* were included in *Your personal melanoma diary* (PMD) to enable participant self-assessment and monitoring of needs. Using an electronic reminder system, participants were prompted to complete screening at three-monthly intervals and as needed. This aimed to motivate survivors to seek assistance should they identify areas of concern. A participant survey regarding self-assessment at three and nine months found that uptake was limited:

 At three months, 45/104 (RR 43%) responded to the survey: 13/45 (38.2%) reported completing the self-assessment. • At nine months, 27 participants answered the survey (RR not reported) and 13/27 (44.8%) reported that they completed the self-assessment. Although not an intended outcome, it was reported that small numbers of partners/carers had completed a self-assessment 'to assess their own needs' (n = 1, n = 3, respectively). Outcomes of self-assessments (for both groups) were not reported for this project.

The AYA project incorporated the Assessment of Quality of Life – 6D for Adolescents (AQoL-6D) (Richardson et al. 2004) at baseline and at three and six months. The AYA Survivorship Screening tool was completed at baseline and at three, six, nine and 12 months. Data continues to be collected by ONTrac at Peter Mac. Preliminary data indicates that physical, emotional and survivorship-specific needs were commonly reported at baseline and follow-up. Fear of recurrence, uncertainty about fertility status and concerns about general appearance were three of the six most commonly identified concerns at baseline and three months.

Of the 46 participants, 43 (RR 93 %) completed a baseline assessment at the time of reporting. At three months 22/43 were eligible for rescreening. Fear of recurrence was the most reported concern at baseline and three months. Refer to Table 2 for the top AYA concerns identified.

Table 2: Top AYA concerns identified

Top concerns identified	Baseline		Three months	
	No.	%	No.	%
Fear of recurrence	32/43	74	14/22	64
Fertility concerns	21/43	49	8/22	36
Concerns about general appearance	21/43	49	8/22	36

A reduction in needs over time was noted for participants in this project. Individual needs dropped significantly from baseline (19.6) to three months (14.8), (p < 0.01). Participants identified 12 areas of information need. Refer to Table 3 for the top information needs identified.

Table 3: AYA top information needs identified

Top 3 information needs identified	Baseline	
	No.	%
Employment assistance	17/43	39
'Ways to improve your health'	17/43	39
Long-term follow-up	15/43	35

AQoL-6D data demonstrated a reduced quality of life for AYA survivors at baseline compared with the healthy AYA population. At baseline, mean quality of life for 39/43 patients (RR 90%) was 0.72 compared with 0.80 reported for the healthy AYA population (Moodie et al. 2009). Quality of life appeared to improve over time; at three months, of those who were eligible for rescreening (21), an overall mean score of 0.84 was reported.

Overall 48 referrals were made at baseline and 12 at three months. The most common referral needs identified were: exercise physiology (21/39; 44%), education and vocation advisor (12/39; 25%) and psychology (8/39; 17%). Of those eligible for screening at three months (18), a small number of referrals were made to each of these services at three months (three per service).

The Moving Forward with Confidence project screened participants using the *Distress thermometer* and problem list at baseline and four months: 51/64 (RR 79%) completed it at baseline and 30/50 (RR 60%) completed it at four months. Fatigue, worry, sleep, memory/concentration and sadness were the most commonly reported problems at both time points. Few (15) participants asked to be referred to community-based services when developing their SCP and 14 participants reported receiving referrals. Services referred to included smoking cessation services, psychologists, dietitians and financial counselling services.

The Positive Change for Life project did not report on supportive care screening outcomes. The focus was on measuring and improving physical activity levels and nutrition.

#### **Enablers**

- Embedding supportive care screening into usual care
- Staff experienced in the assessment process
- Using screening tools appropriate to the population to be screened such as adapting the screening tool to capture AYA population needs
- · Providing tools in the survivor's first language

# Challenges

- Screening tools validated for use in the post-treatment timeframe aren't available
- The concept of survivorship has not been well understood by the lay community this affects the translation of resources into other languages.

#### John's story (not the participant's real name)

Early in 2011, John 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 nine months a diagnosis of osteolymphoma was revealed. Six months on John had completed his cancer treatment but found it impossible to continue his studies or play in the band. He recognised his quality of life was significantly affected by his chronic fatigue and pain, and 12 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 get his life back on track. John was assisted to connect with a local GP who could support him to manage his health. John says the survivorship project has been incredibly beneficial in helping him recover his physical fitness and develop ways to cope.

Barwon South West Survivorship Project participant

# 5. Risk-stratified pathways

Through the screening in the project many young people have been identified and referred for psychotherapy. I have been able to successfully work with these young people to support them with some of the many challenges they face in survivorship that may otherwise have been overlooked... 7

AYA project psychologist

#### Key messages

- Agreed risk stratification criteria and pathways are essential to determine the appropriate model and place of care.
- Risk stratification pathways provide guidelines only; one size does not fit all.
- Supportive care needs assessment tools can inform risk stratification.
- Pathways need to incorporate processes for rapid access back to specialist care.
- Service- and survivor-level barriers to change can impact on embedding risk stratification pathways.
- Reorientation of healthcare providers and survivors and creating a shared understanding of the new roles require a cultural shift.

Designing efficient cancer follow-up to meet individual needs is supported by stratifying patients according to risk, tumour type, treatment and personal circumstances. Watson et al. (2012, p.1) define risk stratification as 'the process of quantifying the probability of a harmful effect to individuals resulting from a range of internal and external factors (e.g. demographic characteristics, genetic make-up, medical treatments)'. They caution that risk is not that same as (healthcare) need, which is the capacity to benefit from healthcare.

Risk stratification was considered by all of the VCSP projects. Varying approaches to risk stratification were employed; however, the underlying principles remained the same. The projects aimed to ensure appropriate targeting of survivorship efforts and to optimise the use of limited resources. Based on needs assessment and stratification and according to the focus of individual projects, appropriate place of care would be identified, model of care, follow-up frequency, healthcare needs would be predicted and a personalised care plan would be developed in collaboration with the survivor. Appropriate preventive and chronic care service referrals would be made.

The Breast Cancer project developed a risk stratification pathway for women at the completion of their treatment for early breast cancer including ductal carcinoma in situ. Risk stratified pathways were agreed by the clinical leads of the service. Patients suitable for inclusion in the project were identified early at a multi-disciplinary meeting. Supportive care needs assessment data also informed risk stratification. Patients at low risk of recurrence were transitioned to shared care with a GP nominated by the survivor.

The delivery method for NLC follow-up (face-to-face or telephone delivery) was also determined using risk stratification. Supportive care needs assessment data and the number of adjuvant treatments received determined whether survivors were offered a face-to-face NLC appointment.

For more information on the Breast Service Pilot Model refer to Appendix 8.

The Barwon South West Survivorship Project intended to develop a risk stratification tool. They acknowledged that few tools were available to inform this work and that a 'one size fits all' cancer risk assessment tool would be too generic or extremely complex. Clinicians determined eligibility for GP follow-up/shared care on a case-by-case basis.

The Melanoma project highlighted the absence of clear evidence to guide risk stratification of melanoma survivors. They developed a table detailing melanoma risk factors; suitability for GP follow-up was determined using the table to guide decision making. Clinical and histopathological factors were considered in determining risk of recurrence. Histopathological factors associated with lower risk of recurrence were as follows:

- < 1.0 mm Breslow thickness</li>
- absence of ulceration
- low-risk mitotic rate = 0.

Consenting participants were transitioned to GP follow-up. The table was provided to GPs to inform follow-up practice. Refer to Table 4 for an outline of the risk factors considered in stratifying melanoma survivors.

Table 4: Melanoma project risk factors to guide stratification

Clinical factors	✓ if identified	Histopathology factors	✓ if identified
History of multiple primaries		Low risk: < 1.0 mm Breslow thickness	
Naevi count > 200		Intermediate risk: 1.0-3.0 mm thickness	
Dysplastic naevi count > 10		High risk: > 3.0 mm thickness	
Hypopigmented primary tumour		Ulceration present	
Body site		Low-risk mitotic rate = 0	
Male		Medium-risk mitotic rate = 1-4	
Elderly		High-risk mitotic rate = 5 or more	
Local/regional metastatic disease			

The Breast Cancer, Barwon South West Survivorship and Melanoma projects acknowledged changes in a survivor's health can impact the appropriateness of shared care follow-up. In response, a rapid re-access process was incorporated into their risk stratification pathways to accommodate changes in health status.

The Melanoma project reported that no participants required rapid re-access to the Victorian Melanoma Service during the project timeframe. One participant indicated dissatisfaction with the recommended follow-up schedule provided. Through discussion with their nominated GP, follow-up was modified to include additional follow-up appointments with an oncologist. Complete data specifying the number of participants requiring rapid re-access to specialist care was not available for either the Breast Cancer or Barwon South West Survivorship projects.

AYA survivors (AYA project) and bone marrow transplant recipients (Positive Change for Life project) were assessed as at high risk of experiencing late effects and long-term treatment impacts. For these groups, routine follow-up care remained with cancer specialists within the acute sector. The focus was on assessing unmet needs, collaborative care with the GP and health promotion.

#### **Enablers**

- Clinical leadership/health professional champions to authorise risk stratification guidelines
- Commitment to develop care pathways and address overcrowded outpatient clinics
- Multidisciplinary approach and workforce awareness and education
- Rapid re-access process
- Introducing survivors early to the risk-stratified pathway of care
- · Increased length of time since completion of treatment and no indication of disease progression

### Challenges

- Lack of GP engagement in development of risk stratification pathway
- Lack of evidence to guide risk stratification across tumour streams

# 6. Survivorship care plans

#### Key messages

- Embedding SCP delivery in usual care relies on organisational support, staff commitment, dedicated time and consideration of IT solutions.
- SCPs are a valued resource and communication tool for survivors and health care professionals.
- Needs assessments are essential for formulating SCPs.
- SCPs could be delivered in a variety of contexts.

Hewitt et al. (2006) in the landmark Institute of Medicine (IOM) report recommends the following content is included in the treatment summary section of SCPs: diagnosis, treatment, outcomes, supportive services needed during the treatment phase and a key acute health service point of contact. It recommends that the follow-up care plan section includes: toxicity screening; other preventative cancer screening; late and long-term effects; and possible signs of recurrence or development of second cancers. Ideally an SCP is commenced in the acute care phase of treatment and continues on through to the 'recovery-survivorship' phase (Salz et al. 2012). McCorkle et al. (2011) suggest SCPs should be designed around a self-management support model that focuses on patient knowledge and optimises healthy behaviour options for future self-care. SCPs are a key tool designed to facilitate role clarity and communication between the survivor, oncology team and GP. It is recommended that SCPs are tailored to individual needs and tumour type.

All projects developed SCPs in partnership with survivors. The name and format of the plan varied, including 'Follow-up care plan' (Breast Cancer project), 'Your personal melanoma diary' (Melanoma project) and 'My health and wellbeing plan' (Moving Forward with Confidence project). This report considers qualitative feedback about the value of SCPs in the context of the broader intervention of which they are a part. Broadly, SCPs were positively received and viewed as a valuable communication tool by participants, hospital-based healthcare professionals and GPs. Some projects indicated that SCPs were viewed as a tool to motivate participants to self-manage and take an active role in their healthcare.

It was noted across the projects that not all participants discussed their plan with their GP. GPs were more likely to discuss the SCP with the participant if it was presented in a model of shared care. Some projects specifically attempted to link the SCP to GP 'chronic disease management plans' and 'team care arrangements' (Australian Government Department of Health 2014). Presentation of information in chronic disease management terms was sometimes used to assist in translation of the SCP to a GP chronic disease management plan. There was limited data collected to evaluate the success of these strategies. Time to develop and implement SCPs within existing resources was viewed as a challenge for sustainability in most projects.

#### For most projects:

- SCPs were delivered at one time point only (i.e. they were not 'living' documents that can be updated)
- the IOM recommended elements of prevention, surveillance, intervention and care coordination were included, although the emphasis varied across projects.
- survivors were asked to make an appointment to discuss their SCP with their GP.
- hardcopy SCPs and/or one-page summaries were sent to GPs.

### Some projects:

- developed and delivered SCPs following a nurse consultation
- included additional correspondence to the GP detailing that the survivor was participating in a survivorship project
- evaluated the use of SCPs over time, with many survivors still using and referring to their SCP after more than three months
- reviewed and updated the SCP at identified time points over many months.

Refer to Appendix 7 for a summary of SCP elements.

Common outcomes were reported from SCP interventions across the projects. Key themes for outcome data included:

- patient acceptability/usefulness
- specialist/healthcare professional response
- communication with GPs
- · health service impact.

## Patient acceptability/usefulness

#### **Breast Cancer project**

- 120/184 (RR 65%) women who attended the NLC returned surveys. Of these, 90 (75%) had seen their GP since the NLC and 78 (70%) had discussed their plan at this appointment.
- From semi-structured interviews with 20 women, participants reported a mixed response to SCPs; some participants (numbers not recorded) had filed it away and not referred to it.

### Barwon South West Survivorship Project

- 84/99 (RR 84%) participants completed an evaluation one week following the NLC. Of these, 69/84 (82%) reported SCPs were helpful or very helpful.
- At three months 74/99 (RR 75%) participants had completed an evaluation; 48/74 (64%) continued to use SCPs.
- After three months 48/74 (64%) indicated the NLC and SCP helped them to understand follow-up and know where to access further support.

#### Melanoma project

- 45/104 (RR 43%) completed an initial evaluation at three months; 28/45 (62%) participants
  reported the personal melanoma diary to be useful or very useful; 26/44 (59%) reported using
  the diary.
- At the nine-month follow-up evaluation (RR not reported), of those who answered the question, 82% (28/34) reported using the diary.

#### AYA project

- 28/43 (65%) participants were eligible to complete an end of project survey. 15/28 (RR 53%) participants reported that they understood the information in the SCP.
- · A minority of participants reported they had discussed their SCP with a hospital nurse or doctor.

#### Moving Forward with Confidence project

 43/50 (86%) participants returned post-evaluation surveys; 30/43 (69%) indicated they received information regarding the impact of cancer, cancer treatment and the likelihood of recurrence through developing their 'My health and wellbeing plan'.

#### Specialist/healthcare professional response

The Barwon South West Survivorship, Melanoma and AYA projects reported positive health professional responses to SCPs, but due to small sample sizes, this data is not reported here.

#### Communication with GPs

#### **Breast Cancer project**

- In qualitative evaluation interviews with 20 GPs, improving pathways for information and communication has been outlined as an important outcome from this project.
- GPs supported the use of a follow-up care plan in managing a woman's ongoing health and support needs and valued the partnership with the breast service.

#### Barwon South West Survivorship Project

- 50/79 (63%) of GPs responded to a survey about the SCP. Almost all (48; 96%) found the surveillance guide useful in ongoing care, with 49 (98%) reporting that the format of the SCP was useful and 44 (89%) believing the schedule provided appropriate information to assist long-term care of their patients' health.
- At project completion, 45/79 (RR 59%) GPs returned surveys. Of these, 37(83%) thought the SCP motivated survivors to take action to address their health needs, 44/45 (97%) GPs used chronic disease management plans in their practice and 40/44 (90%) of these GPs indicated SCPs were useful in developing chronic disease management plans and/or team care arrangements.

#### Melanoma project

• GPs most commonly referred to the diary, followed by dermatologists (detailed data not reported).

#### AYA project

• 14/15 GPs and medical specialists (RR not reported) who provided feedback reported using the SCP in discussions and follow-up consultations as 'most useful'.

#### Moving Forward with Confidence project

- 22/57 (RR 38%) GPs returned surveys; 21/22 (95%) supported the concept of self-management plans for cancer survivors and 20/22 (90%) believed the plans would be useful to patients in managing their health needs.
- 4/22 GPs (18%) reported wanting an online version of the SCP.

#### Positive Change for Life project

 GPs were mailed a copy of the SCP and information regarding survivors' participation in the project. GPs were encouraged to regularly guide, supervise and monitor survivors' progress.

# Health service impact

#### **Breast Cancer project**

Approximately 2.5 hours was required to prepare and deliver the SCP for each survivor. Diagnosis
and treatment history data was extracted from MDM summaries and completed by data
managers. It was, however, noted that information technology (IT) incompatibility impacted
on the time taken to develop plans.

#### Barwon South West Survivorship Project

- IT capability enabled SCPs and letters to GPs to be individualised and allowed some autopopulation of information for the SCP; however, IT limitations impacted on efficiency.
- Time to fully complete the SCP was seen as a challenge.
- Overall, up to five hours was required to complete and deliver the SCP with each survivor, including two NLC appointments, health education and making relevant referrals.

#### Melanoma project

- Health professionals involved in completing and delivering personal melanoma diaries reported a limited impact on their workload (numbers not reported).
- Organisational support and the commitment to improve shared care improved implementation.

#### AYA project

Generating initial SCPs took on average 54 minutes (not including delivery time). Time differences
were noted across sites, primarily related to IT infrastructure. In the absence of electronic record
support, SCPs took up to 180 minutes to complete (not including delivery time). It was unclear
whether familiarity with SCP development processes reduced the time taken to generate SCPs.

#### Moving Forward with Confidence project

• Developing the initial SCP took between 90 and 120 minutes.

#### **Enablers**

- · Validation of the role of SCPs in addressing unmet survivorship needs by lead clinicians
- Allocating equal importance to the survivorship and acute care phases
- Organisational support and commitment to deliver SCPs
- Embedding SCPs as key communication tools specifying the roles of GPs and survivors in follow-up
- Appropriate IT solutions

# Challenges

- Absence of IT solutions; differences in time taken to complete SCPs across sites due to absence
  of electronic records and poor system compatibility
- Time to populate and deliver SCPs, make referrals and liaise with GPs
- Translation to GP chronic disease management plans
- Limited data about potential long-term survivor outcomes



The pilot projects employed a variety of models and delivery mechanisms and interventions. An underlying principle was to incorporate shared care or community partnerships. This aimed to transfer aspects of survivorship care from the acute sector to GPs or the community sector.

Recruitment numbers varied across the projects, which impacts on the interpretations of the data discussed in this section. Specific details of models are listed in Table 5.

Table 5: Models of care features

Project features	Breast Cancer project	Barwon South West Survivorship Project	Melanoma project	AYA project	Moving Forward with Confidence project	Positive Change for Life project
Number recruited	184	84	103	46	64	53
Time since end of treatment	6–12 months post-diagnosis	Most more than two years	EOT	EOT	Within 12 months	Two years post-treatment
Metropolitan	<b>V</b>		<b>~</b>	V	<b>V</b>	<b>V</b>
Regional city		<b>V</b>		V		
Rural		<b>V</b>	V			
CALD survivors	<b>V</b>				~	
Cancer specialist lead	~		V			<b>~</b>
NLC	<b>V</b>	<b>V</b>				
Other health professional led				Care coordinators, nurse, social workers, radiation therapist	✓ Nurse, attempted to engage allied health	✓ Dietician, exercise physiologist if indicated
Shared care GP	V	V	~			
Discharge to GP		V	V			
Engage GPs in holistic survivorship support				~	V	~
NGO partnership					V	
NGO affiliation	V		V	V	~	V
Hospital-based	V	V	V	V	V	V

Project features	Breast Cancer project	Barwon South West Survivorship Project	Melanoma project	AYA project	Moving Forward with Confidence project	Positive Change for Life project
Community partnership					~	V
Self- management support model					V	V
Face-to-face*	<b>V</b>	<b>V</b>	<b>V</b>	<b>V</b>	<b>V</b>	<b>V</b>
Telephone*	<b>~</b>	<b>V</b>		<b>V</b>	<b>V</b>	<b>V</b>
Email*				✓ Rural survivors		
Risk stratification	~	<ul><li>Medical decision – individual basis</li></ul>	V	V		
SCP development	~	V	V	V	V	Available in pre-existing late effects clinic
Number of hospital-based consultations	1	2	1	7	4	5
Care pathway developed	~	~	~	~		

CALD = culturally and linguistically diverse; EOT = end of treatment

<sup>\*</sup>Consultation or follow-up



#### Key messages

- Strong clinical leadership and project management principles are key to enabling implementation.
- Shared care initiatives that are conceived by primary care or in partnership with primary care may better utilise existing chronic disease management infrastructure.
- Nurses in primary care have a role in providing chronic disease management interventions and facilitating shared care communication.
- Incorporate one-page summaries and processes for rapid re-access.
- Prepare survivors early during the treatment journey for shared care follow-up.

Shared care is a model in which both the specialist and GP provide care (Oeffinger & McCabe 2006). Shared care approaches can provide preventative healthcare, greater usage of community-based healthcare resources, increased communication between survivors and GPs and decreased pressure on access to specialist providers (Health Workforce Australia 2011). It can result in reduced specialist clinic appointments for low-risk survivors and increase service capacity for those with complex needs and those with a new diagnosis (NHS Improvement 2012).

The Breast Cancer, Barwon South West Survivorship and Melanoma projects piloted shared care models. These models were conceived and led by the acute health system; however, they were steered and implemented in close consultation with consumers and primary care organisations (Inner North West Medicare Local, Barwon Medicare Local, Great South Coast Medicare Local, Gippsland Medicare Local and the Peninsula General Practice Network).

As noted earlier, these projects incorporated SCPs, supportive care screening and a rapid re-access pathway for participants requiring referral back to specialist care. In consultation with GPs, each project developed a one-page treatment summary including recommendations/requirements for GP follow-up. Two of these projects (Breast Cancer and Barwon South West Survivorship projects) included NLCs that facilitated transition to shared care through direct liaison with the relevant general practice. All projects enabled participants to be active partners in decision making to transfer to shared care.

Limited data was collected to define survivor outcomes from GP shared care arrangements. On face value, high levels of acceptability and satisfaction with shared care/discharge to GP follow-up were reported by most participants, with most electing to continue with shared care. System and health service outcomes were difficult to report given the limited timeframes of the projects.

The Breast Cancer project planned to transition 184 survivors to GP shared care (the number who successfully transitioned to shared care was not reported). The following outcomes for survivor participants were reported:

• 105/120 (88%) participants surveyed reported that they 'consider their GP and hospital to be partners in their ongoing follow-up care'.

- 85/120 (71%) participants surveyed reported that they had 'a better understanding of what they could do to keep themselves well' following their initial GP appointment (RR not reported).
- A sample of 20 participants completed telephone interviews between nine and 12 months
  following NLC consultation. Some were unclear about what shared care meant and had not
  visited their GP. The report did not indicate whether these participants discontinued shared
  care follow-up.

Health service and system-level outcomes were also reported. Breast care nurses and surgeons anecdotally reported that the shared care process allowed a comprehensive plan of follow-up appointments to be developed, reducing unnecessary appointments. Modelling suggested that an average of one to two fewer hospital appointments per year will be required for participants enrolled in shared care. This demonstrates the potential to reduce hospital follow-up costs for significant numbers of low-risk breast cancer survivors and allow resources to be directed to those with more acute needs. The participating health services are continuing to implement breast cancer shared care follow-up. Aspects of the breast project model have been incorporated within a new project piloting discharge to GP follow-up for survivors with low-risk endometrial cancer.

The Barwon South West Survivorship Project transitioned 43 of the 99 NLC attendees to GP shared care arrangements or discharge to GP follow-up. Of these, all were haematological or breast cancer survivors and most were more than two years after the end of treatment. For rural survivors in particular, the project predicted greater convenience accessing follow-up care closer to home (potentially reducing transport and parking costs and appointment waiting times). As it was not possible to develop a single risk stratification framework across multiple tumour streams, cancer specialists determined who would be eligible for shared care/discharge to GP follow-up. This project has been extended to enable the engagement of additional tumour streams, ongoing recruitment and evaluation.

The Melanoma project demonstrated high levels of acceptability with GP shared care arrangements, with 104/107 (97%) of survivors consenting to participate. It was reported that the Victorian Melanoma Service specialists engaged well with the shared care model. At the system level, the project team highlighted the potential to free up appointments for new/more urgent patients by transferring follow-up for significant numbers of low-risk melanoma patients to GPs.

#### Other partnerships with GPs in cancer care

Although all projects sought to engage GPs in collaborative survivorship care, not all projects aimed to transition medical follow-up care from specialists to GPs. Some projects continued standard cancer specialist follow-up and sought to engage GPs in holistic survivorship support. Specifically they asked GPs to:

- be engaged in health promotion or chronic disease management approaches to prevent/delay late effects
- develop and oversee a GP chronic disease management plan and team care arrangement
- support survivors to action health and wellbeing goals.

These projects sought to engage GPs to undertake roles they already perform with patients with other diagnoses. They asked GPs to recognise potential physical and psychological impacts of cancer and to support survivors with these impacts.

The AYA project aimed to strengthen GPs' knowledge of challenges facing AYA survivors, long-term health risks and resources appropriate for the AYA population. It also sought to educate AYA survivors regarding the value of having a regular GP involved in their care.

The Positive Change for Life project aimed to facilitate communication of holistic survivorship needs and to engage GPs to support health promotion and chronic disease prevention goals.

#### **Enablers**

- Cancer specialist interest in transitioning follow-up care to the primary care setting
- Strong relationships and partnerships established/ fostered with GPs
- SCPs as a communication tool defining roles, responsibilities and allocating follow-up tasks
- Confidence of GP in providing follow-up care to cancer survivors
- Education packages linked to GP continuing professional development points
- · Alignment with chronic disease management and preventative healthcare frameworks
- Risk stratification pathways with a clear rapid re-access process
- · Confidence of participant in the GP's ability to manage their ongoing care
- Community-based allied health services to support GP shared care
- GPs with an interest in survivorship care

- Ensuring that survivors understand what shared care means in practice
- Identifying survivors who see more than one GP or change GPs, to ensure effective follow-up and communication
- Projects without formalised GP shared care arrangements reported lower levels of GP engagement

#### 7.1.2 Engagement with primary care - process

#### Key messages

- Primary care needs to be integral to project design and implementation.
- Conceptualising survivorship care within chronic disease management may assist in engaging primary care.
- A strategy (developed with/by primary care) is required to communicate survivorship health impacts and shared care pathways and roles.
- Opt-out approaches to obtaining GP consent to participate in shared care arrangements are easier to implement.
- Statewide or national policies could assist in embedding shared care approaches once a clear evidence base has been established/ demonstrated.

#### **Engagement strategies**

Common strategies to engage GPs included:

- · consulting with General Practice Victoria
- utilising established links with key GP representative bodies (Royal Australian College of GPs, hospital GP liaison officers, GP practice organisations, GP network organisations)
- GP and/or GP network representation on steering committees
- seeking GP feedback individually and collectively
- supporting the use of Medicare item numbers to facilitate remuneration for GPs involved in followup care
- developing/utilising existing GP education resources (including online modules and contracting GP education providers)
- writing articles for GP newsletters or creating newsletters for GPs and primary care nurses and publishing shared care arrangements on GP websites
- speaking at GP network events
- communicating survivors' needs through SCPs
- engaging with GPs individually (phone/fax/email) regarding survivors' needs
- providing information (written/verbal) to survivors encouraging them to remain engaged with their GP and consent to shared care arrangements.

The projects encouraged survivors to raise cancer-related concerns and continue routine follow-up care with their GPs. Survivors were encouraged to initiate engagement and discuss their SCPs and physical activity and nutrition goals with their GPs.

In addition, the AYA project developed written information highlighting the importance of GPs for young people and provided participants with a list of 'youth friendly' GPs. Contrary to evidence suggesting that many young people are not engaged with a GP (Booth, Knox & Kang 2008; Jarrett et al. 2011), the AYA project found that the majority of participants had an existing relationship with a GP. This reflected ONTrac at Peter Mac requirements that young people accessing their service engage a GP.

#### Consent to shared care

Two of the projects attempted to engage GPs to provide written consent to shared care arrangements. Both projects experienced difficulties engaging GPs in this process. The Breast Cancer project found that some GPs were hesitant to sign the shared care agreement without first speaking with the survivor. Some GPs were unaware that survivors had already consented to GP follow-up. In response to these challenges, the Breast Cancer project routinely informed GPs that participants had consented to shared care and adopted an opt-out approach whereby GPs notified the project team if they were unable to participate.

The Melanoma project did not request GP written consent; instead GPs were provided with a letter and project information advising that their patient had consented to participate in the project. GPs were asked to support their patient following the management plan outlined in the letter from the Victorian Melanoma Service. The letter indicated the stage, prognosis, risk stratification factors and surveillance plan and was intended to educate and influence GPs regarding recommended follow-up.

Engagement and communication with GPs presented challenges across all of the projects. Despite this, some projects provided qualitative evidence of successful communication between cancer specialists and GPs. Some survivors also reported positive experiences engaging with GPs in survivorship care.

#### **Breast Cancer project**

- 46/162 (RR 30%) GPs returned surveys.
- Formalised survivorship care planning was well received by GPs (numbers not reported).
- Some GPs were unclear of their exact roles/responsibilities (numbers not reported).
- Qualitative interviews were completed, with 20/162 (12%) GPs indicating that providing holistic follow-up care for survivors following their hospital treatment was part of their role (numbers and selection process not reported).
- A small number of GPs were not aware of the rapid referral pathway for re-entry to acute care (numbers not reported).
- GPs valued the partnership with the breast service (numbers not reported).
- Improved pathways for information and communication established in response to GP feedback.

#### Barwon South West Survivorship Project

- 60% of GPs were able to be contacted by phone to discuss shared care arrangements.
- Anecdotal reports suggest that involving primary care nurses in developing chronic care plans and following up survivors aided care coordination.
- Anecdotal reports suggest success using 'chronic disease language' with GPs.

#### Melanoma project

 GP surveys were returned by only five GPs, limiting the ability to utilise feedback from GPs (RR not reported; however, 103 survivors were recruited).

#### AYA project

 The project reported that 42/43 (97%) AYA participants who completed baseline interviews had a pre-existing relationship with their GP and 52% had contact with their GP within nine months of baseline screening.

- Feedback on the Patient Experiences Questionnaire (PEQ) at three months (n = 12,) from
  AYA participants indicated a satisfactory outcome to the consultation with their GP, a positive
  communication experience, a lack of communication barriers, a positive experience with auxiliary
  staff and a positive emotional experience.
- Several participants did not attend a GP review (despite prompts) (numbers not reported).
- Nine GPs (RR not reported) indicated that the intervention was useful and the SCP was helpful and clear but was not generally used in their discussions with AYA participants.
- GPs supported the role delineation with cancer specialists adopted for this project but were divided in their feedback about whether they wanted to have more input into SCPs (numbers not reported).

I think this program is one of the reasons that I have such a good connection with my GP. It certainly encourages me to utilise my GP.

AYA project participant

#### Moving Forward with Confidence project

- 22/57 (RR 38%) GPs returned surveys.
- 14/22 (63%) would prefer to receive SCPs as part of a discharge summary.
- At post-intervention interview, 43/50 (RR 86%) survivors reported that no GPs discussed the plan in detail with them.

#### Positive Change for Life project

- Surveys were returned by 28/51 (RR 55%) participants at nine months.
- 14/28 (50%) initiated a discussion with their GP about physical activity or nutrition goals.
- 19/28 (71%) stated their GP asked them about their progress and more than 50% reported receiving encouragement and feedback during the consultation.
- The project team reported challenges engaging GPs using chronic disease language; anecdotally some GPs reflected a view that stem cell recipients should be wholly managed by specialist care.
- Attempts to pilot a survivorship-specific GP management plan or team care arrangement that could be imported into GP practice software were not successful.

#### Enablers

- Publication of clear shared care guidelines (risk stratification, follow-up and surveillance schedules and roles and responsibilities)
- Direct involvement of GPs in the writing of shared care guidelines
- Involvement of primary care staff to facilitate communication
- Development of succinct, common documentation and processes
- Remuneration for attending project steering committees
- GPs' perception that follow-up care is part of their usual role
- High incidence, low-risk groups seen more regularly in GP practice (such as melanoma/ skin cancers)
- Cancer specialists may be more receptive to shared care for patients who are two years or more post-treatment
- Strong pre-existing relationships with primary care providers

#### Challenges

- Lack of risk stratification guidelines defining who should receive GP follow-up
- · Cancer specialist/GP perceptions that cancer-related needs are out of scope for general practice
- Lack of reciprocal communication between GPs and cancer specialists (for example, challenges for GPs communicating investigation results to cancer specialists)
- Limited formal agreement in transfer of care
- Cancer specialists agreeing to GP shared care arrangements without receiving written consent from GPs
- Survivors who have no GP or multiple GPs
- Survivors poorly prepared for shared care and lacking confidence in GP follow-up

### 7.2 Nurse-led clinics and care coordination approaches

#### Key messages

- NLCs can facilitate transition to GP shared care but were not required for all models.
- NLCs were well received by participants and facilitated supportive care screening, needs assessment, tailored information provision and care coordination and referral.
- Telephone-delivered interventions by nurses are acceptable to patients.

Two of the six projects (Barwon South West Survivorship and Breast Cancer projects) provided NLCs following active treatment. NLCs were viewed as a means to manage increasing demand on clinics. The projects aimed to sustain these clinics through transitioning low-risk medical follow-up to the primary care setting, thereby increasing cancer specialist clinic access for new patients (see Table 6).

Table 6: Nurse-led clinic characteristics

Clinic	Breast Cancer project	Barwon South West Survivorship Project
Location	Metropolitan health services	Three regional and rural centres
Number of appointments	1	2
Appointment time	6–12 months post-diagnosis	Within two years of the end of treatment
Review of disease, pathology, treatment and follow-up requirements	<b>V</b>	<b>V</b>
Administration of screening tools including supportive care screening	V	V
Focus on education regarding management of treatment side effects and late/long-term effects	✓ Includes promotion of BreaCan Navigator app for information on a range of topics (breast cancer)	~
Participant provided with SCP including personalised follow-up plan	V	V
Option to access telephone- delivered nurse intervention	✓ Risk-assessed provision of telephone-delivered nurse intervention  Women who received more than one modality of treatment or reported significant psychosocial concerns were eligible for the face-to-face clinic; others were stratified to telephone follow-up	
Referrals to services initiated	✓ Includes linkage with BreaCan	✓ Focus on linkage with community-based allied health professionals

Both projects reported high levels of survivor and health professional satisfaction with the NLC intervention.

#### **Breast Cancer project**

- 119/184 (RR 65%) survivors who attended NLCs responded to surveys; 98 (83%) 'did not feel that they still had issues they needed help with'.
- BreaCan conducted 20 telephone interviews and reported 'overwhelmingly positive' feedback
  and general agreement that the timing of the NLC was appropriate. 'For many, the NLC signified
  an opportunity to talk about what they were experiencing in order to recognise that their ongoing
  issues were normal' (numbers were not reported).

Anecdotally, NLCs were perceived as 'a suitable model to elicit health issues at treatment
completion and successfully promoted/prescribed referrals to cancer NGOs/other community
services'. Success was not limited to only consultations where the participant knows the nurse/
healthcare professional.

#### Barwon South West Survivorship Project

- 84/99 (RR 85%) survivors completed questionnaires one week following the NLC
- 75 (90%) reported that the two consultations with the nurse were 'helpful' or 'very helpful'.
- 64 (77%) reported contact with the nurse would help them raise issues with their healthcare provider.
- 42 (51%) reported that they received referrals for other services from the nurse.

Cancer specialist survey findings (RR not reported):

- 12/12 rated a moderate to high level belief that the NLC achieved its aims.
- 11/12 rated the ability of the clinic to enhance continuity of care between specialists as moderate to very high.
- 11/12 rated the clinic's ability to provide a survivor-centred approach as high to very high.

Nurses, radiation therapists and allied health professional survey findings (RR not reported):

- 11/14 rated the sustainability of the model of care as high to very high.
- 12/14 believed the project improved post-treatment care for their patients.

It was a very informative appointment to help proceed with the next stage of my life. **3** 

Keep up the good work as it is hard to have someone with time to listen to your concerns about your cancer and the results of its side effects. "

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.

Barwon South West Survivorship Project participants

#### Other care coordination models

The projects did not compare the efficacy of NLCs with other models of care. The Moving Forward with Confidence and AYA projects provided nurse and care coordinator-led interventions respectively (although interventions were not provided in an NLC). The Moving Forward with Confidence project sought to engage allied health professionals but limited resources impacted on allied health involvement. The AYA project engaged care coordinators of varied backgrounds (nurses, social workers and radiation therapists) to develop SCPs with participants.

#### AYA project

 Based on project team experiences, they reported that 'the value lies in providing dedicated time with a trusted professional to discuss areas of immediate concern and to provide a point of contact for future concerns'.

- Overall outcomes regarding care coordinator interactions were positive. Feedback on the Patient Experiences Questionnaire (PEQ) at baseline (n=32), and three months (n = 17,) reported a positive communication experience; a lack of communication barriers; and a positive emotional experience.
  - o 28/43 (65%) participants were eligible to complete the end of project survey.
  - o 15/28 participants responded at time of report writing.
  - 12/15 reported that their understanding of survivorship had improved.
  - All reported their survivorship needs had been met.
  - o 13/15 reported that they were better able to access support.
  - o 8/15 reported that their ability to manage their healthcare had improved.

There were mixed responses across the projects in terms of preferred appointment scheduling. Some Breast Cancer project participants declined NLC appointments because they did not want to attend additional appointments. The Barwon South West Survivorship Project scheduled additional appointments (not aligned with specialist appointments), while the AYA project reported that appointments were better received when added to existing appointments.

#### **Enablers**

- Cancer specialist authorisation of NLCs and willingness to refer survivors
- Infrastructure and resources to support clinics
- · Cancer nurses and allied health professionals with a strong interest/experience in survivorship care
- Education of nurses about available allied health services relevant to survivors, referral criteria and requirements
- Education of care coordinators about primary care chronic disease management models and the role of primary care nurses

- There is no clearly identified revenue stream for NLCs under the current funding models
- It is unclear whether there are cost benefits for substituting NLCs for medical follow-up
- Lack of recognition of allied health roles in survivorship models of care
- · Limited acute and community-based allied health resources



#### Key messages

- Establishing stronger linkages between health services and cancer-related NGOs improves access to services for survivors.
- Engaging cancer-related NGOs enables flexible provision of survivorship support over time.
- The vision and culture of cancer-related NGOs can align well with delivery of supported self-management and wellbeing interventions.
- Community partnerships support the development of high-quality information resources for survivors.

Most of the projects worked closely with community-based organisations. Some were project partners who were integral to project development and others had a consultative role. Organisations included representative consumer bodies (such as Melanoma Patients Australia, the Victorian and Tasmanian Youth Cancer Advisory Board and CanTeen), cancer-related NGOs (such as BreaCan, the Leukaemia Foundation and Cancer Council Victoria) and community-based fitness centres (YMCAs and private fitness service providers).

Despite differences between projects, shared aims of partnerships were identified:

- · consulting with consumers to ensure projects/tools were designed in response to needs
- promoting project interventions to survivors
- developing information resources for survivors
- strengthening referrals/linkages for survivors and improved access to peer support.

#### **Breast Cancer project**

- Collaboration with BreaCan led to the creation of an online referral system to enable breast care nurses to directly refer women to BreaCan through its website.
- 120/184 (RR 64%) project participants completed surveys. Of these, 96 (80%) reported BreaCan
  as their main resource apart from their GP or breast care nurse and strongly agreed it was useful.
- BreaCan developed a number of navigator tools on topics including: after mastectomy, breast forms, breast reconstruction, fertility preservation, surgery, radiotherapy, chemotherapy, hormonal treatment, lymphoedema, sexuality and intimacy, healthy eating and exercise and life after treatment.
  - A website and app for use on a smartphone or tablet was developed to optimise access to the navigator tools.
  - 16 surveys were returned by participants, GPs and health professionals; respondents rated the navigator tools positively (excellent or good) (numbers not reported).

#### Melanoma project

• Collaboration with Melanoma Patients Australia informed the development of the 'Your personal melanoma diary' and influenced project design.

#### AYA project

 Collaboration with the Victorian and Tasmanian Youth Cancer Advisory Board and CANTEEN enabled the development of the AYA Survivorship Resource and AYA information for GPs.

The Moving Forward with Confidence and Positive Change for Life projects partnered with community-based organisations to deliver survivorship interventions. This enabled provision of services to survivors over eight- and 12-month periods respectively. Both projects sought to deliver wellbeing-focused interventions.

The Moving Forward with Confidence project partnered with Cancer Council Victoria helpline nurses providing follow-up telephone calls to survivors. This partnership enabled tailored, flexible provision of information, support, coaching and referrals. It proactively engaged survivors in conversations that were wellness-focused, rather than cancer-focused.

It was anticipated that sharing treatment summary information with the helpline nurses would be critical for supporting survivors. In practice, the helpline nurses reported that survivors rarely sought to discuss specific disease and treatment information. Survivors engaged with the helpline service to address supportive care needs, find out about what they could do to remain healthy and to learn how to find services to address their needs.

The Moving Forward with Confidence project reported the following partnership outcomes:

- The project provided the ability to provide timely information, support and linkages to survivors
  over an eight-month period. The helpline nurses readily transitioned to providing self-management
  support interventions and demonstrated high utilisation of motivational interviewing skills. The
  vision, mission and culture of Cancer Council Victoria aligned well with this model of care.
- Participant response to helpline follow-up included:
  - 43/50 (RR 86%) survivor participants completed post-evaluation surveys:
    - 35 (81%) reported that the helpline service contact was helpful to them
    - 39 (91%) reported that the helpline called at a time that was convenient
    - 30 (70%) felt contact with the helpline helped keep them motivated to work on their wellbeing.
  - Variable preferences were reported for the timing of telephone interventions.
  - The level of survivor engagement varied.
  - There were high levels of engagement with and a positive impact from follow-up calls reported by survivors experiencing depression/anxiety/challenges dealing with difficult emotions following cancer (numbers not reported).

The Positive Change for Life project partnered with the Leukaemia Foundation and community-based fitness centres to provide effective diet and physical activity interventions that were cost-neutral for survivors. The program provided telephone-based dietetic consultation based on the Coach for Heart Health model (The Coach Program 1995) and fitness programs tailored to individual survivor's needs and preferences. Survivors accessed local fitness and recreation facilities 'normalising' physical activity after cancer.

Partnership outcomes for the Positive Change for Life project included:

- effective engagement with community-based fitness centres to support improved provision of services for survivors of haematological cancer
- group and individual sessions and various kinds of physical activity memberships for survivors
- 13 allied health professionals and service providers reporting positive feedback regarding project funding flexibility, education and identification of barriers to physical activity for survivors (and selfmanagement strategies to address these barriers)
- ongoing commitment of the Leukaemia Foundation to provide diet and physical activity interventions to survivors of haematalogical cancers beyond this project.

#### **Enablers**

- Collaborative project development and inclusion of community organisations on steering committees
- Alignment of project aims with cancer-related NGO organisational vision
- Piloting and understanding the resource implications of interventions and models
- Flexibility in allocating resources and redesign approaches can facilitate partnerships
- Informing survivors of cancer-related NGO services early.

- Availability of resources/infrastructure for community partners to sustain interventions
- Awareness of and confidence in cancer-related NGO services
- Internal organisational changes (of philosophy, priorities, staffing, etc.) that can impact on project delivery

## 8. Health literacy

#### Key messages

- Health literacy affects survivors' ability to engage in self-care and chronic disease management activities.
- Health literacy impacts on healthcare costs.

Health literacy is not routinely measured in healthcare; however, there are negative consequences for cancer care, general health and health services associated with limited health literacy (Nielson-Bohlman, Panzer & Kindig 2004). Following a comprehensive review of the literature on the importance of health literacy in cancer care, Kaoy, Schofield and Jefford (2012) reported limited health literacy as a risk factor for poorer health outcomes. They linked poorer understanding of health information to increased stress, reduced wellbeing and difficulties in articulating concerns with health professionals. They added that survivors with lower health literacy may be less inclined to participate in disease prevention and health promotion activities. For example, people with poor health literacy may not understand the relationship between lifestyle factors such as diet and exercise and various health outcomes.

Screening for health literacy is time consuming and not always achievable in the clinical setting. Baker (2006) advocates using a 'universal precautions approach' whereby it is assumed that all patients experience some degree of difficulty in understanding health information. The basic principles of plain language, communication tools and assessment of comprehension apply to all.

Two projects measured health literacy and the impact of health education. The Health Literacy Questionnaire (Barwon South West Survivorship Project) (Osborne et al. 2013), the Health Literacy Management Scale (Moving Forward with Confidence project) (Jordan et al. 2013), and the Health Education Impact Questionnaire (both projects) (Osborne, Elsworth & Whitfield 2007) were selected. Both projects reported high levels of health literacy in participants at baseline and demonstrated positive shifts in the short term for some domains of health literacy and health education impact. In the setting of high health literacy, the challenge lies in choosing tools that are sensitive to measure positive change. Project health literacy outcomes are reported in section 9.

Great to... be reminded of other readily available resources... Unless you are in the system you don't know what is actually available. ??

Made me aware of the need to watch for any symptoms [and] to discuss them with doctors.

Barwon South West Survivorship Project participants

#### **Enablers**

- Using sensitive screening tools appropriate to the population to be screened
- Providing tools validated for use in the survivor's first language
- Selecting short practical measures
- Using mHealth (mobile phone devices) and other information provision approaches to improve cancer health literacy

- Non-English-speaking and CALD populations
- Time constraints associated with screening
- Identifying validated reliable tools in this setting/population
- Ensuring tools are sensitive to the needs of individuals and data obtained informs delivery of interventions such as adapting information provision for survivors with low health literacy
- Survivors being poorly informed about what to expect post-treatment and community-based services relevant to their needs.

## 9. Impacts on survivor self-management

#### Key messages

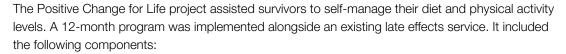
- Supported self-management models involve a major shift for acute health services and require multi-level organisational change strategies.
- Target resources: not all survivors require self-management support interventions.
- Promote self-management during treatment.
- Consider readiness to self-manage when risk stratifying survivors.
- Utilise existing chronic disease management and coaching programs.
- Partnerships with existing community-based fitness services, rehabilitation services and cancer-related NGOs can support survivors to self-manage.

A diagnosis of cancer may act as a catalyst for re-evaluating health behaviours. This may provide a 'teachable moment' or opportunity to motivate survivors to make positive lifestyle changes (Demark-Wahnefried et al. 2005). Macmillan Cancer Support (2012) recommends that supported self-management be adopted as a central tenet of risk-stratified survivorship care. Supported self-management may provide a cost-effective means of catering for the needs of large groups of survivors. A Macmillan review found interventions that targeted survivor self-efficacy and included survivor-generated goals were more effective than those that provided information and support alone (Davies & Batehup 2010). Models for delivering supported self-management interventions are applied to people living with chronic conditions (McCorkle et al. 2011). In Victoria, the application of these models to cancer survivors is in its infancy.

Most of the projects sought to assist survivors to self-manage their health, although most did not incorporate evidence-based self-management support models. Strategies used to promote self-management included:

- providing tailored information
- teaching specific skills (for example, self-examination for melanoma recurrence)
- referring to community health and rehabilitation services and cancer-related NGOs
- including survivor-generated goals.

Two of the six projects (the Moving Forward with Confidence and Positive Change for Life projects) delivered longer term supported self-management interventions incorporating self-management support/coaching models. The Moving Forward with Confidence project targeted survivor self-efficacy and engaged survivors to develop and action wellbeing goals. The project considered survivor readiness to make changes, confidence in their ability to achieve goals and the perceived importance of goals. Motivational interviewing was used to promote behaviour change.



- an individually tailored community-based physical activity plan (including gym/fitness centre/water exercise memberships, walking schedules, pilates and yoga)
- group physical activity
- motivational strategies and GP support
- education
- a dietetic consultation based on the Coach for Heart Health model (face-to-face sessions at baseline and after 12 months and telephone-delivered coaching three times over eight months).

Refer to Appendices 5 and 6 for evaluation tools used in the Moving Forward with Confidence and Positive Change for Life projects.

Across most of the projects it was reported that participants engaged positively with information resources and a small number indicated making changes to physical activity levels, diet and alcohol consumption. Some of these participants attributed these changes to participating in the projects, although the absence of control groups for most projects and short evaluation timeframes limits the ability to draw definitive conclusions about the impact of interventions.

#### Reported outcomes/feedback from survivors

#### **Breast Cancer project**

• 120/184 (RR 65%) participants returned surveys; 46/120 (39%) reported making lifestyle changes as a result of an NLC appointment (primarily diet and exercise changes).

#### Barwon South West Survivorship Project

- In the Health Literacy Questionnaire (HLQ) all 98 (RR 100%) participants responded at baseline –
   84 (86%) at one week and 74 (76%) at three months. Significant increases were demonstrated in three out of nine domains at one week and three months:
  - 'perceived healthcare provider support' (p = 0.025)
  - 'critical appraisal' (p = 0.001)
  - $\circ$  'navigating the healthcare system' (p = 0.04).

#### AYA project

- 15/28 (RR 53%) participants completed end of project surveys:
  - 86% reported that they were better able to access support
  - o 50% felt their ability to manage their health had improved.

#### Moving Forward with Confidence project

- 57/64 (RR 89%) participants completed baseline interviews and 43/50 (RR 86%) completed postevaluation interviews at six months.
- At baseline, 51 (90%) thought that developing a plan and goals would help them to manage their health.
- At post-intervention, 36 (86%) believed that the intervention had positively impacted on their ability to manage their health.

- Statistically significant change at post-intervention was found in 1/8 domains on the HeLMs: 'patient's attitudes towards their health'.
- Statistically significant improvements were found in two HeiQ domains at post-intervention: 'positive and active engagement in life' (p = 0.010) and 'emotional wellbeing' (0.020).
- 38 (88.4%) participants reported that they 'developed goals and strategies during the intervention.
- 36 (86%) responded that 'developing goals and strategies helped them to return to activities that were important to them', 'or take up new activities'. For example, 28/50 participants reported that they achieved exercise goals.
- 34 (79.1%) thought they developed new knowledge, skills or strengths due to the intervention.

It's worked for me. You know it's got me thinking about the cancer, everything that I want to change ... it's been slow but I'm just seeing the benefits now ... I went to a 50<sup>th</sup> on Saturday night and didn't drink or smoke.

Moving Forward with Confidence project participant

#### Positive Change for Life project

- Project participants reported high levels of acceptability and value for the program.
- Outcomes included increased physical activity levels, improved nutrition, weight loss, reduced fatigue and enhanced quality of life (including physical, emotional and functional wellbeing) for the majority of participants.
- At baseline all 53 (100%) participants were assessed; 10 (20%) were sufficiently active to produce substantial health benefits. At six months this figure increased to 61% in the 41/51 (80%) assessed and physical activity levels were associated with improvements across quality of life domains including emotional and functional wellbeing and overall quality of life.
- At program completion (12 months) 38/50 (76%) were assessed. Overall physical activity increased (p < 0.001), as did moderate and strenuous activity (p < 0.001) and activity sufficient to work up a sweat (p = 0.025).
- Higher physical activity levels at 12 months were significantly associated with reduced self-reported fatigue, improved physical wellbeing and enhanced self-efficacy scores at both six and 12 months. At 12 months they were also significantly correlated with reductions in unhealthy eating behaviours, improved nutrition scores and healthier lipid profiles.
- Most beneficial outcomes occurred for participants within the initial six months of the project and were maintained up to six months following completion of the 12-month exercise program.
- 32 late effects clinic attendees who did not participate in the project demonstrated increased net weight gain, percentage body weight, body mass index and abdominal circumference at their routine 12-month visit (note: the project did not use randomisation).

Refer to Appendix 9 for detailed project outcomes.

Health professionals' capacity to promote self-management in survivors

Reporting of health professionals' capacity to promote survivor self-management was limited to the Moving Forward with Confidence project. In this project nurses were mentored in motivational interviewing skills.

#### Reported outcomes for nurses

- The small number of health professionals involved in this project limits definitive conclusions.
- All five nurses who participated in post-evaluation surveys/focus groups recorded high levels of confidence in their ability to promote survivor self-management.
- The helpline nurses demonstrated a shift in focus from information provision to self-management support using motivation interviewing techniques.
- Focus group feedback indicated that they selectively applied this model to other helpline callers.

Yes, the project did alter my workforce role and shifted the focus of interactions from information provision to collaboration and support. It allowed me to work autonomously and expand my skill set in a way that enhanced my other client interactions. **)** 

I think ... I'm more inclined to ... be attuned to change talk and ambivalence – the concept of rolling with resistance rather than bashing up against it and asking people what something would look like or would involve – getting them to visualise what an ideal thing might be and what would need to happen for that to eventuate was – they were different things ... I'm generalising but nurses are action-oriented problem solvers so the concept of enabling and saying I'm not the expert here ... but it's really about picking the person. That's something about motivational interviewing, it's really not a tool you use for everybody all of the time but it is in your grab bag of skills that used at the right time can be really helpful for you. \frac{1}{2}

Helpline nurse focus group feedback

#### **Enablers**

- Incorporating self-management support approaches earlier (during treatment), including provision of rehabilitation and potentially (by extension) pre-habilitation
- Confidence in and awareness of the potential role of GPs/other community providers such as exercise physiologists and dietitians
- Access and defined referral processes to allied health professionals, rehabilitation and healthy lifestyle programs
- Developing resources for survivors that target increased self-management
- Utilising partnerships with community-based organisations including cancer-related NGOs and fitness centres
- · Inclusion of survivor-generated goals
- Involvement of partner/carer
- · Use of accurate and sensitive measures to measure the impact on self-management capability
- Strategies to facilitate motivation and confidence to action wellbeing goals

- Survivor readiness to self-manage
- Reorientating health services and health professional practices to deliver evidence-based self-management support interventions
- Changing health service culture to promote self-management
- Resourcing longer term interventions
- Limited timeframe to measure the cost benefits of healthy lifestyle interventions
- Measuring achievement of varied personally defined wellbeing goals
- Timing interventions for maximum benefit

## 10. Carer outcomes

#### Key messages

- Carers play a significant role in health promotion and disease prevention.
- Consider including carers when developing and evaluating survivorship interventions.

The projects did not target carers' needs as this was not overtly specified in the grant application guidelines or program objectives. The long-term impact of a cancer diagnosis on families and carers is increasingly recognised, as is the role carers play in supporting self-management (Stenberg, Ruland & Miaskowski 2010). The critical role of carers became more prominent as the projects progressed. Some projects invited participants to include carers in their nurse-led consultation; however, uptake was limited. Most projects did not seek carer consent for participation, so carer feedback could not be obtained.

The Melanoma project did not actively recruit carers, although, with participant consent, carers were educated regarding skin self-examinations and encouraged to assist with the task. It was noted that three partners or carers completed a screening tool to record their own needs, although screening of carers was not intended. The outcomes of screening undertaken by carers were not reported.

Some projects sought carer feedback (AYA project and Positive Change for Life project). The AYA project results highlighted that AYA carers have significant unmet needs that are currently not adequately addressed within the healthcare system. Issues can originate during the cancer treatment trajectory and new issues can emerge post-treatment, such as fear of recurrence. The project also highlighted the value of young people sharing their SCP with family members.

The Positive Change for Life project identified the critical roles carers play in the post-treatment period and the benefits that carers may gain from participating in recommended healthy lifestyle activities. The project team acknowledged common long-term problems experienced by cancer survivors that increase their risk of future chronic illness. These long-term problems are also prevalent in the general population (including carers). A high proportion of carers (85%) reported observing improvements in their family member's fitness, energy, physical activity and eating habits. They stated they had personally benefited from their family member's participation in the project through increased awareness of the benefits of nutrition and physical activity and developed healthier eating habits.

#### **Enablers**

- · Acknowledgement of the impact of the carer role in education and support of the survivor
- Incorporating carers into survivorship programs

- · Lack of recognition of the experiences of carers in cancer
- · Some carers do not identify as a 'carer'
- · Carers not prioritising their needs or asking for help

## 11. Workforce education

#### Key messages

- It is critical to educate and prepare the workforce for survivorship care.
- Education delivery needs to be flexible.
- Align education with specific health professional needs and organisational culture.
- Education programs need to have reasonable objectives.
- Align education programs to patient-reported outcomes.

Cancer survivorship education, training and support are critical. Collaboration between oncology and primary care bodies to develop educational resources can assist in transitioning care and result in survivorship-focused discussions with survivors (Oeffinger & McCabe 2006; Blanch-Hartigan et al. 2012).

All projects recognised workforce education as key to implementing and sustaining their models of care. It was considered essential to equip specific healthcare providers with the skills and confidence to undertake survivorship care and to support a self-management approach. The learning needs of health professional groups were not assessed; however, a range of educational activities were intended to target health professional groups that worked directly with cancer survivors.

Educational aims included increasing awareness of survivorship issues, introducing the projects and communicating progress. Overall it was anticipated that participation in these targeted educational activities would inform health professional practice. Most projects did not teach specific skills. Some projects reported challenges engaging GPs to attend educational activities. Generally, most projects either did not report on these outcomes or used limited evaluation measures. This report is unable to comment regarding the impact of education initiatives.

A variety of approaches to education were piloted across the projects:

- The Breast Cancer and Barwon South West Survivorship projects collaborated with GP liaison
  units and raised awareness of their models of care. The Breast Cancer project organised half-day
  professional development events to inform GPs of the shared care follow-up model for women
  with early breast cancer.
- The Melanoma project engaged with GP education providers to consult on the development of an active e-learning module for GPs, offering tailored education regarding melanoma diagnosis and survivor management. The module comprised two components, the first of which is an online education module. Following this, GPs can access a clinical attachment with private or public specialist providers in their region. Continuing professional development points are allocated on completion of this module. Eight GPs participated in the Melanoma project learning module. A letter sent to GPs was also reported as an education tool.
- The AYA project involved ONTrac at Peter Mac providing specific AYA training and ongoing support for project care coordinators. Multidisciplinary case discussion was also utilised as a learning environment. The project incorporated survivorship into the AYA educational program for medical students at Peter Mac.

- The Moving Forward with Confidence project provided 15 (nursing and allied health) staff with a one-day education session. Nine nurses also participated in up to five mentoring sessions in self-management support skills. The mentoring sessions aimed to create reflection about readiness to change, shift the balance of interactions to one of shared expertise between health professional and survivor and assist health professionals to begin to use motivational interviewing skills to strengthen motivation for goal attainment.
- The Positive Change for Life project aimed to provide GP education but experienced engagement difficulties that precluded the delivery of planned education sessions.

In addition to these projects, a number of activities and forums for workforce education are in place:

- Australian Cancer Survivorship Centre (ACSC) website
- Primary health care Nurse Education (ACSC, Cancer Council Victoria and Think GP websites¹)
- Survivorship Health Professional Forum
- Survivorship module (Cancer Learning website).

The ACSC also established educational activities to support the project teams. Other health professionals are eligible to join these forums:

- Survivorship shared online workspace
- VCSP community of practice.

#### **Enablers**

- Targeting educational resources to the specific needs of healthcare providers
- Time provided to complete the education package
- Obtaining recognition for professional development points
- Education provided in an accessible format
- Forums/infrastructure that facilitate sharing of information and support survivorship care implementation

- Lack of validated evaluation of educational programs
- Engaging GPs to attend survivorship education

<sup>\*</sup> Think GP websites education modules are no longer active

## 12. Economic evaluation

#### Key message

 Developing a strong business case supports the implementation of new models of care.

It is important to understand the direct and indirect costs associated with a cancer diagnosis, treatment and follow-up. Understanding the impact of diagnosis, treatment, the potential for late and long-term effects and how associated costs are borne and shared by individuals and the healthcare sector may inform decisions regarding the economic value of interventions.

The projects did not engage health economists or business analysts; however, it is recognised that developing a strong business case is important. More detailed analyses were not undertaken, so data is of limited value in assessing the economic value of these projects.

The shared care/discharge to GP follow-up projects predicted a cost shift from acute care to primary healthcare. The Breast Cancer project completed preliminary modelling that suggested the number of routine visits for hospital appointments decrease from four to two over a two-year period. They attribute this outcome to addressing unmet needs and moving care into the primary care sector, thereby avoiding unnecessary hospital visits and promoting a GP shared care agreement for holistic care. This improved access to the cancer service for new patients. The Barwon South West Survivorship Project attempted to undertake an economic assessment using a cost-outcome approach, but the results were inconclusive. Across the projects, small participant numbers affected the capacity to report on economic outcomes.

Literature supports the potential of healthy lifestyle interventions to be cost-effective in preventing late complications and the development of other health-related issues for cancer patients (Davies, Thomas & Batehup 2010; Lajous et al. 2010). The Moving Forward with Confidence project proposed supported self-management as an effective cost-efficient approach for care of survivors who are at a lower risk of serious and persistent survivorship difficulties; however, the project did not measure economic impact. The Positive Change for Life project demonstrated improved health outcomes for both participants and carers and considered the potential longer term health system savings associated with preventing/delaying the onset of chronic diseases but did not evaluate this. Longer term studies are required to enable a full economic evaluation to be undertaken.

#### **Enablers**

- · Economic evaluation as an outcome criteria
- Expertise in economic evaluation/business case development
- Common evaluation framework
- · Longer timeframe for projects

#### Challenges

Small participant numbers

## 13. Sustainability

Developing sustainable and transferable models of care/interventions was critical. Projects were asked to develop interventions that could be delivered within existing resources. Each of the projects considered sustainability in designing their interventions, although the extent to which projects developed strategies for sustainability varied. Some projects experienced challenges simultaneously, researching novel interventions and developing longer term implementation strategies. Three projects are continuing to evaluate sustainability. The projects reported a number of interventions as sustainable, however, did not always report data to support this assertion. Due to the lack of evidence reported, it is difficult to predict ongoing sustainability for some aspects of project interventions. The three GP shared care/discharge to GP follow-up projects have the potential to deliver sustainable models of follow-up care.

The project teams report the following in relation to sustainability.

#### **Breast Cancer project**

The participating breast services have embedded all aspects of the shared care model into standard practice. Approximately 2.5 additional hours per patient were required for NLC interventions; however, participants were predicted to require an average of two to four fewer medical (hospital-based) appointments over a two-year period. The project demonstrated success in establishing clear risk stratification pathways for women with low-risk breast cancer and continues to embed these pathways in partnership with local primary care organisations. A guideline on breast cancer care for health professionals that clarifies pathways and processes is in development.

It is noted that work is underway to extend this model to other breast services in Victoria. Lessons from this project were considered transferable to a new project involving discharge to GP follow-up for women with endometrial cancer. This is currently being tested.

#### Barwon South West Survivorship Project

The project team reported that the project has the potential to be sustainable. The project highlighted the importance of the following determinants of sustainability:

- improved IT capacity to support SCP generation
- the continued presence of cancer specialist champions and tumour stream support
- ongoing culture change enabling acceptance of survivorship care within acute cancer services including promotion of survivorship services from the point of diagnosis (as appropriate)
- organisational support
- continued engagement with key GP organisations and individual GPs.

It is noted that the host agency has supported a time-limited extension of the project to allow the model to be embedded and to develop a business case for ongoing funding. The model will be introduced in another region. A challenge for sustainability lies in resourcing the nurse-led intervention under current hospital funding models. The Barwon South West Survivorship Project plans to pilot a small group-delivered NLC appointment. Survivors will then access an individual NLC appointment if they have further needs. This has potential to enable improved efficiency and targeting of nursing resources. More work is required to develop risk-stratified pathways across tumour streams that will enable more survivors to transition to shared care/discharge to GP follow-up.

#### Melanoma project

The project team reported that sustainability of the Melanoma project intervention is supported by the following factors:

- existing Visiting Medical Service clinicians absorbing additional tasks into existing consultations
- self-management support tools (PMD, skin self-examination education and inexpensive SMS reminder system)
- large numbers of low-risk melanoma survivors who can be stratified to receive GP follow-up
- traditional GP roles encompassing assessment of skin lesions as a result of the high prevalence of skin cancers in the Australian community.

Challenges with GP engagement made it difficult to evaluate the perspective of primary care providers regarding the sustainability of this model.

It is noted that while this model would appear to be sustainable on face value, additional data is needed to strengthen understanding of the impact and sustainability of this model.

#### AYA project

The AYA project reported developing an AYA survivorship care pathway that appears to be feasible and sustainable. Specifically the following sustainable elements were reported:

- AYA survivorship screening and assessment
- survivorship care planning where the health service resources support this activity
- supporting youth-friendly primary care engagement for AYA patients
- providing regular review and screening in the first 12 months post-treatment completion
- · development of age-appropriate resources.
- They identified the following factors as influencing sustainability:
- ongoing provision of education to a broad range of health professionals
- presence/absence of an electronic health record at participating sites
- capacity to allocate additional resources.

It is noted that this model is resource-intensive and reflects the higher level of engagement that AYA survivors may require. However, the model is well supported at Peter Mac by the specialist AYA service. Further work is indicated to determine whether providing seven review appointments to survivors across health services with fewer AYA-specific services will be sustainable.

#### Moving Forward with Confidence project

The project reported that the intervention is not sustainable within existing resources in its current format. The project did not shift provision of care from hospital to community, at least in the short term; rather it increased demands on both services. The development of initial SCPs and the delivery of helpline follow-up calls were very difficult to deliver within existing staffing. Challenges to sustainability for the helpline service included:

- the time needed to deliver follow-up interventions and exchange information with health services,
   GPs and participants
- balancing an outcall service with unpredictable incoming calls
- the need to reschedule calls and difficulties accessing participants

- the preference of participants to engage when assistance was required, rather than at prescribed follow-up points
- lack of risk management regarding the impact of staff turnover.

Providing a risk-stratified 'call in' service may provide a more sustainable approach. Focus group feedback from the helpline service suggested the following:

- Helpline nurses could provide supportive care and wellbeing-planning interventions independently
  of SCP interventions.
- Alternative methods of delivery of educational, goal setting and motivational interviewing interventions could strengthen sustainability (such as group programs and apps).
- The role that community-based organisations occupy in providing this type of intervention for survivors is poorly understood by health services.

It is noted that this project was not sustainable, although there may be potential to trial self-management support approaches using different models. The project sought to raise awareness of the positive benefits of using targeted motivational interviewing and developing survivor-generated goals. As a result, a participating site developed and is piloting a four-week group survivorship intervention using this self-management support model. Reorientating acute health services to delivering self-management support interventions requires broader organisational change approaches and sustainability strategies.

#### Positive Change for Life project

The project reported that the partnership between the late effects clinic and the Leukaemia Foundation was key to enabling sustainable delivery of the program. The most successful elements of the Positive Change for Life project have been integrated into the Leukaemia Foundation's 'Jump Start' program (Sostaric & Polack 2014). Jump Start is a 12-week physical activity and nutrition program available to all survivors of haematological cancer (regardless of treatments received). The benefits of physical activity and nutrition programs have been established for colorectal, breast and prostate cancer survivors. This model could be applied to other tumour groups.

It is noted that project funding enabled delivery of cost-neutral fitness centre memberships to be available for a 12-month period. The challenge lies in engaging survivors in programs that will incur out-of-pocket costs or finding innovative ways to fund or partially fund longer term exercise programs. The Jump Start program will provide a cost-neutral 12-week program; some survivors may need to self-fund exercise beyond the 12-week timeframe. Although this model holds promise, ongoing evaluation of shorter exercise programs in terms of outcomes/effectiveness and the sustaining of exercise routines beyond 12 weeks may be required. Cancer-related NGOs may have an expanding role in implementing these models with other tumour groups.

#### **Enablers**

- Capability to develop and embed agreed risk stratification pathways
- · Capacity for existing medical, nursing and allied health EFT to participate in survivorship care
- Development of long-term relationships and partnerships with GPs in survivorship care
- Development and maintenance of survivorship-specific knowledge and skills across health services and primary care

- Alignment of project interventions with cancer-related NGO objectives and capacity of NGOs to allocate resources to interventions
- The ability to allocate resources to maintain and update information provided to survivors

- Time required to deliver holistic survivorship care
- Limited vision/ leadership to redesign cancer care within acute health services
- Identifying ongoing funding streams or models of care
- Inefficiencies in SCP generation (ability to electronically populate treatment summaries, limited targeting of SCPs)
- Small numbers of some survivor populations
- Delivering resource-intensive interventions in rural areas to smaller numbers of survivors

# 14. Workforce evaluation

The comprehensive *Evaluation report of the VCSP projects: A workforce perspective* was undertaken by the Australian Health Workforce Institute (Naccarella & Freijser 2014). Copies of this report can be obtained through the ACSC. The report examined the six pilot projects. The evaluation did not assess the acceptability, quality or efficiencies of the pilot models or the interventions. It was noted that the projects were not funded as workforce reform and innovation projects.

Data collection activities utilised:

- · development of a workforce profiling logic model
- participation in VCSP community of practice meetings
- meetings with VCSP pilot project teams and their evaluation teams
- three rounds of interviews with project managers and lead clinicians
- two rounds of interviews with key stakeholders and GP representatives.

The evaluators made recommendations for policy, practice and research. These recommendations are summarised in Appendix 10.

## 15. Recommendations

The VCSP projects were designed to pilot and evaluate new models of care. Implementing survivorship care in Victoria is a work in progress. The pace of change is slow; extended timeframes are required to embed new models and more work is required to delineate roles and responsibilities. The projects highlight the potential to support survivors through partnerships with primary care and community organisations. Further work to align cancer with chronic disease management and secondary prevention models utilised by primary care is recommended. Conceptualising future projects in primary care may facilitate engagement.

As detailed throughout this report, evaluation frameworks were limited and this impacts on the ability to draw definitive conclusions from these projects. Despite this, common enablers and challenges for implementing a variety of survivorship interventions have been identified. These enablers and challenges need consideration when planning future survivorship projects. The following recommendations are worthy of consideration in planning future survivorship initiatives.

#### 1. IT solutions

Develop IT systems solutions to identify survivors prior to the end of their treatment and to populate treatment summaries.

#### 2. Prepare survivors early for what might be expected following treatment

Prepare survivors early for what might be expected during survivorship and how to access assistance if problems arise. Early preparation for GP follow-up will help survivors to accept shared care arrangements. Information resources could be developed to communicate these messages. There is a need to modify survivorship terminology for individuals and cultural groups who do not identify with the terms 'survivor' or 'survivorship'.

#### 3. Improve access to structured needs assessment and care coordination following treatment

Overall, survivors valued the opportunity to discuss their supportive care needs, to find out about relevant services and to learn what they could do to self-manage and stay well. Supportive care needs include physical, social, informational, spiritual and psychological needs. Across the projects, survivors identified a range of concerns across most domains; some concerns were interrelated. Analysing needs assessment data enables identification of common and specific concerns post-treatment across individual groups such as tumour groups and CALD groups. This may help in developing tailored resources/initiatives.

Screening and needs assessment tools need to be developed and or validated in the survivorship setting to assist in this process. Incorporating a needs assessment at the end of treatment could be considered in the context of Victorian supportive care policy. Some survivors benefit from repeat screening over time to capture development of late effects and delayed onset adjustment challenges.

Consideration of needs in the context of self-management ability and cancer health literacy supports health services to:

- risk stratify survivors
- · direct resources to those most in need
- coordinate care
- provide opportunities for tailored self-management support.



- provide timely access to rehabilitation
- identify survivors who require support from exercise physiology, dietetics and group exercise programs
- link survivors with cancer-related NGOs.

#### 4. Support self-management

Acute health approaches are poorly aligned with self-management support models; major cultural change is indicated. A system-wide change management approach is required.

Recommendations for building survivors' capacity to self-manage include:

- empowering patients to identify and report problems and to be active decision-makers earlier during treatment
- communicating the importance of adopting healthy lifestyle behaviours (nutrition, physical activity, etc.) during and at the end of treatment
- strengthening linkages with chronic disease self-management programs provided in the community
- enhancing survivors' ability to proactively access services in response to late and longer term effects
- educating survivors about the importance of actively participating in medical follow-up
- addressing longer term survivorship needs (beyond the post-treatment timeframe) and piloting programs for these groups.
- piloting and evaluating chronic disease management programs with people with advanced or recurrent disease.

#### 5. Utilise partnerships with community-based organisations

- Strengthening linkages between acute cancer services and cancer-related NGOs can support improved survivorship care. Partnerships can:
  - strengthen the consumer voice in developing models of care and project tools/information resources
  - link survivors with group interventions, exercise interventions, peer support and internet-based information and support
  - o provide flexible access to support and information when survivors identify concerns.
- Engaging community fitness centres in delivering physical activity programs for survivors could promote the health benefits of exercise, extend the reach of exercise support and improve fitness.

#### 6. Workforce education

- Provide education about survivorship needs and evidence-based interventions to address these needs.
- Target acute cancer services, general practice, rehabilitation and community-based allied health services.
- Increase awareness of the relative contribution of each of these services/sectors and healthcare professional groups to survivorship care.
- Consider engaging a range of health professionals to deliver survivorship interventions (including nursing and allied health professionals).

- Develop a toolbox to support health services to create and implement survivorship programs. Linking with existing UK initiatives may assist.
- Consider establishing a community of practice across partners and other organisations with an interest in survivorship care to share learning and resources.

#### 7. Recommendations for evaluating future survivorship projects

- Develop rigorous evaluation plans and align tools with the key program objectives. Achieving larger sample sizes may strengthen the evaluation findings and provide evidence for future projects.
- Identify a suite of evaluation tools that could be adopted across projects to enable comparison of interventions/models.
- SCPs need to be evaluated in the context of the wider intervention that they are delivered within and what they aim to achieve.
- Evaluate the longer term impact of survivorship models of care on survivor experience and health service delivery.
- Collect data to measure the acceptability and effectiveness of interventions for CALD and Aboriginal survivors.
- Follow survivors who become lost to follow-up (within traditional and new models of care) and describe their demographic profiles.

# 8. Shared care and discharge to GP follow-up have the potential to increase specialist clinic capacity to manage growing numbers of survivors.

Shared care/discharge to GP follow-up models appear to be acceptable to low-risk cancer survivors. Further work is required to:

- identify sustainable business cases for models of shared care across high prevalence, low-risk groups
- evaluate the economic impact of shared care/discharge to GP follow-up
- evaluate the longer term impact of shared care/discharge to GP follow-up on survivor outcomes.

#### 9. Risk stratification

- Use risk stratification approaches when developing and tailoring a range of survivorship interventions (self-management support, psychology, nurse-led, etc.).
- More evidence is needed to establish risk stratification guidelines across tumour groups that may be suitable for shared care/discharge to GP follow-up.
- Work to extend risk-stratified survivorship approaches to broader groups of survivors (varied tumour types, CALD, Aboriginal and rural communities).

# 10. Consider challenges posed for implementing survivorship care within existing resources. The following could support implementation of new models of care:

- Develop national/state policies.
- Adopt redesign approaches.
- Use change management models.
- Provide infrastructure to enable sharing of information and tools.

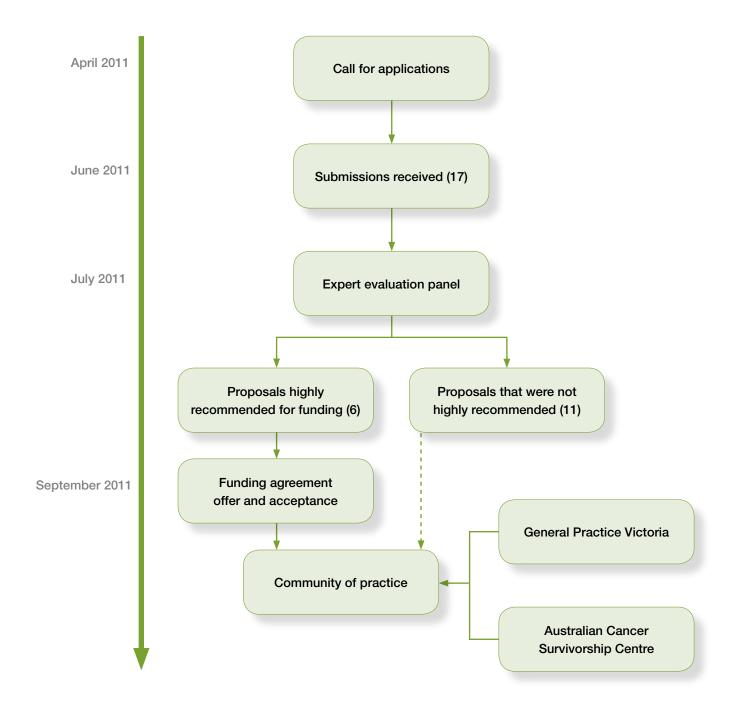
#### 11. Include carers

- Carers have their own experience assess their needs and link with supports/interventions directed at them.
- Recognise that carers are essential partners in chronic disease management.

## 16. Conclusion

Implementing survivorship care in Victoria is a work in progress. Extended timeframes are required to embed new models and roles. Aligning cancer with chronic disease management models and conceptualising future projects in primary care may facilitate engagement. Supporting survivors to self-manage and partnering with community organisations could help health services to more flexibly cater for the needs of increasing numbers of survivors. Considering identified enablers and challenges identified in this report will help when implementing future survivorship initiatives.

# Appendix 1: Diagrammatic view of VCSP selection process





# Appendix 2 VCSP: Pilot projects application guidelines 2011

'Refer to the following pages for a full copy of the Victorian Cancer Survivorship Program: Pilot Projects Application Guidelines'

# health

Victorian Cancer Survivorship Program: Pilot Projects

**Application Guidelines 2011** 

Due Date: Monday 2pm, 27 June 2011



Department of Health

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## 1. Purpose

This document provides an overview of the **Victorian Cancer Survivorship Program: Pilot Projects**. The pilot phase will require the health services within the Integrated Cancer Services to partner with primary care organisations including Primary Care Partnerships (PCP), Divisions of General Practice, General Practitioners (GPs) and non-government organisations in the development and implementation of cancer survivorship pilot projects in phase one of the *Victorian Cancer Survivorship Program* (the Program).

## 2. Background

Victoria's Cancer Action Plan 2008-2011 (VCAP) details targets and milestones for achieving service improvement in cancer care. Action area four focuses on supporting patients and their carers throughout their cancer journey<sup>1</sup>.

The Victorian Government has provided funding over four years to establish the *Australian Cancer Survivorship Centre*, based at Peter MacCallum Cancer Centre. This is a state-wide and nationally-relevant initiative that has been funded in partnership with The Pratt Foundation to foster and develop survivorship care for both cancer patients and cancer care providers.

VCAP also commits to establishing a state-wide program that trials patient-centred models of cancer survivorship care by 2012.

The focus of the Program in the first phase (2011-13) will be on establishing up to five pilot projects to develop and trial sustainable models of survivorship care. The models are required to coordinate and link specialist cancer treatment teams with primary care providers and/or non-government cancer support organisations in order to develop patient-centred approaches to survivorship care.

Selection of the cancer survivorship pilot projects will be through a grant process, as detailed below. Pilot projects for phase one will run for up to two years. Future phases of the Program will build on the outcomes of phase one, and will not commence before July 2013.

# 3. Victorian Integrated Cancer Services

Integrated Cancer Services (ICS) are formal partnerships between health services that have responsibility for coordinating the planning and improvement of cancer services. There are three metropolitan, five regional ICS based on specified geographic populations and one state-wide paediatric ICS. Priority areas for improvement for the ICS include care coordination and to reduce variation in access to and delivery of patient care.

Int	formation on	Victorian cand	er initiatives a	nd ICS	can be	found at	: www.hea	lth.vic.g	ov.au/	cancer
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Department of Health. Victoria's Cancer Action Plan 2008-11

# 4. Cancer survivorship – a definition

There are a range of views about where "survivorship" starts. For many patients, surviving cancer begins on the day of diagnosis, and appropriate support and information during the treatment phase is recognised as an extremely important aspect of care. The literature highlights the end of the initial treatment phase as being a particularly stressful time, when most medical therapies are complete and the reality of living with cancer comes into focus.

Survivorship care, as defined by the Institute of Medicine (USA), is 'the phase of care that follows primary treatment for cancer'. The Institute of Medicine report *From Cancer Patient to Cancer Survivor: Lost in Transition* (2005)<sup>2</sup> describes the following essential components of survivorship care:

- · Prevention of new cancers.
- Surveillance for new or recurrent cancers.
- Detection and intervention for the late effects of cancer and its treatment (medical and psychosocial).
- Rehabilitation and returning to health after treatment.
- Promotion of health and wellbeing and psychological support.
- Coordination of care between specialists and primary care providers.

It is the post-primary treatment phase of the cancer journey that the department is using to define 'survivorship' for the purposes of this grant process.

#### 4.1 Developing models of cancer survivorship care

Developing patient-centred models of cancer survivorship care requires a change in the way that follow-up care for cancer patients has traditionally been delivered. In particular, hospital-based models of follow-up care that focus solely on surveillance of the cancer rather than caring for the patient in the context of their lives are not suited to the longer term follow-up care that is required for many cancer patients.

The National Health Service in England<sup>3</sup> (NHS) describes a number of key shifts that are required in order to improve the care for people living with cancer, as part of its *National Cancer Survivorship Initiative*. These include a shift to:

- · A focus on health and recovery.
- Improving information.
- Assessment and care planning.
- Providing tailored pathways of care based on risk of future problems, type of treatment and individual circumstances.
- · Improved measurement though patient-reported outcomes and experience measures.

Different patients are likely to require different levels of follow-up and surveillance across a continuum of care that includes:

- Hospital based care: follow-up care led by the oncology multidisciplinary team.
- Shared care: combined services of both the acute cancer service and primary care provider.
- Community-based care: delivered/arranged by the primary care provider.

In some cases, particularly where a patient has a complex cancer or is at high risk of recurrence, it is essential for the specialist treating team to provide close and regular follow-up. In many cases, GPs are well-placed to monitor and support patients who are living with cancer, in addition to periodic follow-up by the treating team. GPs are able to refer for a range of supportive care therapies (such as physiotherapy,

<sup>&</sup>lt;sup>2</sup> Hewitt, M., Greenfield, S., and Stovall, E. (eds), Institute Of Medicine and National Research Council of The National Academies. From Cancer Patient To Cancer Survivor: Lost In Transition. The National Academies Press Washington, D.C. November 2005

<sup>&</sup>lt;sup>3</sup> Department of Health, Macmillan Cancer Support & NHS Improvement. The National Cancer Survivorship Initiative Vision. January 2010

rehabilitation, counselling) using the Chronic Disease Management (CDM) Medicare items on the Medicare Benefits Schedule (MBS), as well as providing support for patients' families and carers. In all cases, appropriate care planning and strong communication between the treating team and the primary care team are essential for the development of patient-centred models of survivorship care and follow-up.

There is a growing body of literature and an emerging evidence base regarding shared care models of follow-up and survivorship, which will inform the development of appropriate models within the Victorian setting. The November 2009 issue of *Cancer Forum*<sup>4</sup> (the official journal of Cancer Council Australia and the Clinical Oncological Society of Australia) is dedicated to survivorship issues, and provides a useful source document and summary of Australian activity in this area. Another useful review article *Models for delivering survivorship care* by Oeffinger and McCabe was published in the *Journal of Clinical Oncology*<sup>5</sup> in November 2006.

# Details of the Victorian Cancer Survivorship Program: Pilot Projects 2011-13

The objectives of the cancer survivorship pilot projects for 2011-13 are to:

- Trial cancer survivorship post-treatment shared models of care (incorporating a specific intervention/s) across the acute and primary care sectors, utilising a range of existing services and funding streams (such as the Medical Benefits Scheme including CDM Medicare items) in both hospital and community-based settings.
- Evaluate cancer survivorship models/interventions in regard to their effectiveness, acceptability, sustainability and transferability to different settings. Individual projects will be required to incorporate an evaluation plan and the department will also develop an overarching evaluation strategy which funded projects will be required to participate in.
- 3. Develop resources (for both consumers and service-providers) and recommendations for future strategies to support improvements in follow-up care for people living with cancer.
- 4. Improve understanding of the specific survivorship care needs of different groupings (i.e. tumour stream specific, age/gender-specific, different risk profiles).
- 5. Facilitate cancer survivor involvement and self-management of their care.

Examples of specific interventions might include but are not limited to:

- Development and trialling of survivorship care planning for specified tumour streams (using Australian Cancer Survivorship Centre-endorsed recommendations and templates).
- Establishment of survivorship clinics (with mixed specialist/primary care staff and peer-support opportunities).
- · Rehabilitation and living with cancer programs.
- Trialling innovative models of survivorship care that incorporate primary care, specialist support and peer support models of care.
- Trialling proven models of self-management and patient-centred follow-up (for example from the UK) in the Victorian setting.
- · Use of e-health tools to aid communication and patient self-management.
- Development of a locally-based primary care community of practice for practitioners with a special interest in managing cancer follow-up in the community.

<sup>&</sup>lt;sup>4</sup> Cancer Council Australia. Cancer Forum. pp159-225 Vol 33. No 3. November 2009.

Oeffinger KC, McCabe MS. Journal of Clinical Oncology. Pp 5117-24. Vol 24. No. 32. November 10, 2006.

### 5.1 Engagement with primary care

General Practice Victoria (GPV) will be available to assist applicants to contact relevant Divisions and General Practitioners with an interest in cancer survivorship to ensure their engagement in the early stages of project development (details available from Lenora Lippmann via email at <a href="mailto:lippmann@gpv.org.au">Lippmann@gpv.org.au</a>). Applicants are encouraged to engage general practitioners in the early design of projects (as relevant).

### 5.2 Funding available

The total funding available for the cancer survivorship pilot projects to develop, pilot, evaluate and embed the models is up to \$1.5 million over the next two years. Projects may be of one or two years (maximum) duration.

Up to five pilot projects will be funded. Funding will be capped at a maximum of \$300,000 per project (\$150,000 per annum).

The nominated fund-holder (Administering Organisation) can be any organisation that has a service and funding agreement with the Department of Health. See Eligibility Criteria for details.

The project partners including ICS secretariats, health services, primary care organisations and non-government organisations are expected to make an appropriate commitment and contribution to the projects, including in-kind and/or cash contributions. The contribution of each partner must be clearly described in the project proposals.

#### 5.3 Eligibility criteria

#### **Applicant requirements**

- The lead applicant must be an employee of either the host or administering organisation.
- The applicant or one of the project partners must register for and attend a question and answer session regarding the aims and objectives of this funding process. Details outlined on page 8.
- Applicants must have endorsement for the project from the chair or delegate of the relevant ICS Governance Group(s).

#### Project requirements

- The majority of the project must be completed within Victoria (collaborators may work interstate or internationally).
- Projects must have specific aims and outcomes that align with the objectives in section 5 above, and are achievable in the designated timeframe.

#### Administering organisation requirements

Applicants must make their application under the auspices of a Victorian public hospital, a government funded agency or a non-government organisation with a funding and service agreement with the Department of Health. A single organisation should be designated as the administering organisation. The administering organisation must:

- Certify in the application form that they meet the requirements for receipt of government funding.
- Have in place policies and procedures for the management of public funds.
- · Have in place policies for the proper conduct of projects.
- Provide adequate infrastructure to allow the project to be completed (if also the host organisation).

#### Host organisation requirements

- Applicants must demonstrate there is a suitable environment for the project to be undertaken. It is
  expected that the host organisation will ensure that there is effective governance of the project and
  have a process for evaluating the effectiveness of any governance arrangements.
- Applicants must have the approval and endorsement of the head of the organisation where the majority of the project will be carried out.
- · The host organisation will provide the facilities and infrastructure to undertake the project.

#### **Project principles**

Project proposals will need to align with the following principles:

- · The project has a focus on the end of and/or post treatment phase of cancer care.
- Follow-up care is tailored to meet individual needs and considers diverse population groups.
- Care will be delivered in the community and/or there will be strong engagement with the community sector.
- · The project will have strong engagement with consumers.
- There is linkage of survivors to existing services and 'packages of care' that are tailored to individual needs, which might address physical, psychological, and social needs.
- Specialist cancer clinicians, primary care providers, nursing and allied health providers are engaged in a formalised transition pathway, from the acute to community care settings, and vice versa.
- Self-management strategies for cancer survivors and their families/carers and peer support
  opportunities are included as a component of follow-up care.
- Care is coordinated through timely and effective communication and consideration is given to a range of approaches to support this, including telephone-based, web technologies (such as internet, video linkage) and face-to-face consultations.

## 5.4 Selection criteria

The following criteria will be used for the evaluation of the submitted applications.

	Criteria	Weighting (%)					
1	Alignment with the Victorian Cancer Survivorship Program						
	In particular:						
	How the project meets the objectives and principles outlined in section 5.						
	<ul> <li>The project has a focus on the end of and/or post treatment phase of cancer care.</li> </ul>						
	<ul> <li>Demonstration of effective partnering between:</li> <li>an ICS secretariat, and/or a health service within an ICS and/or</li> <li>a primary care organisation (Primary Care Partnership or Division of General Practice) and/or</li> </ul>	30%					
	o a non-government organisation.						
	<ul> <li>Demonstration of consultation and effective partnering with consumers.</li> </ul>						
	<ul> <li>Demonstration of multidisciplinary and coordinated follow-up care to optimise survivor well- being and improve outcomes.</li> </ul>						
	<ul> <li>How the results of the project will be communicated and disseminated to other clinicians, health services, consumers and health care decision makers.</li> </ul>						
$\vdash$	Demonstration of transferability of the survivorship model to other settings.						
2	Importance of the project						
	The project is designed to address an important problem or need in survivorship care. Specifically:	20%					
	<ul> <li>The significance of the need being addressed in the project.</li> </ul>						
	How the project will result in improved patient outcomes.						
3	Quality of the project proposal						
	Feasibility						
	<ul> <li>Describes a feasible approach, encompassing the above project principles.</li> </ul>						
	<ul> <li>Incorporates an appropriate evidence-base for strategies outlined, and articulates relevant reports, guidelines and policies.</li> </ul>						
	Rationale						
	<ul> <li>Specifies the intervention(s) to be trialled, including a rationale for the need/choice of intervention and the appropriateness of the intervention.</li> </ul>						
	Innovation						
	<ul> <li>Describes how the project is unique in the Victorian health system.</li> </ul>						
	Methodology (including evaluation)						
	<ul> <li>Provides a detailed methodology*, estimated costs and risk assessment (*E.g. an appropriate action research or service redesign methodology). Clear, measurable outcomes are specified, with a focus on patient and system benefits.</li> </ul>	30%					
	Outlines an evaluation strategy for the project, including qualitative and quantitative measures.						
	Sustainability						
	<ul> <li>Demonstrates consideration and commitment to sustainability following the cessation of pilot funding.</li> </ul>						
	<ul> <li>Leverages of other funding sources, for example MBS, for service delivery components.</li> </ul>						
	<ul> <li>Incorporates education and training of relevant staff (e.g. general practitioners and practice nurses) as part of a sustainability strategy.</li> </ul>						
	Timeframes						
	<ul> <li>The projects aims, objectives and outcomes can reasonably be completed in the timeframes specified.</li> </ul>						
4	Capacity to undertake the project						
	<ul> <li>Evidence of applicant's satisfactory completion of previous projects and compliance with project requirements (track record).</li> </ul>	20%					
	Support for conducting the project     Existing infrastructure.     Commitment by senior leadership to achieving the project objectives, including designation	20,0					
	of an executive sponsor for the project and an appropriate governance structure.						
		100%					

#### 5.5 Exclusions

- Projects related to equipment where purchase of equipment is the main component of the project.
- International travel will not be funded through these grants.
- Projects that are currently funded through existing mechanisms or will receive funding through other targeted initiatives.
- Projects where the primary focus is a research intent.

## 6. Evaluation process

Applications will be screened by Cancer Strategy and Development to ensure that selection and eligibility criteria have been met. A receipt of submission will be sent to applicants.

An Evaluation Panel will be convened to assess applications, and make recommendations for funding.

The recommendations from the Evaluation Panel will be considered by the department who will determine the number of applications it is able to fund, its obligations under VCAP, and overall strategic objectives of the development regarding cancer survivorship.

In the event that the department identifies that there are projects that are similar or complementary to each other, the department may request that the applicants consider collaborating on their projects, where appropriate. There is no obligation imposed on the applicants under this condition. Any recommendation that might eventuate from such a suggestion by the department would be voluntary.

The lodging of an application does not confer any entitlement on the applicant. The making of a recommendation is totally within the discretion of the assessment panel and the department.

All applicants will be advised in writing of the final outcome of the selection process, including a summary of the successful cancer survivorship projects for phase one of the Program.

#### **Privacy**

All information contained in applications will be regarded as confidential. Documents containing personal information will be handled and protected in accordance with the provisions of the *Privacy and Personal Information Protection Act 1998*. Personal information will only be disclosed with the permission of the individual to whom it relates, or where the Act allows.

Applicants consent to the information supplied as part of their application being disclosed for the purposes of the evaluation and administration of the grant. Such disclosure includes but is not limited to members of Evaluation Panels, independent readers/assessors requested by Evaluation Panels to provide advice on the applications, Department of Health and Cancer Strategy and Development staff, relevant ICS secretariat staff, and relevant employees of the Victorian Government involved with the grant process.

Applicants acknowledge that announcement of the funded grants will involve the dissemination of information to the public about the general nature of the funded grants.

## 7. Conflict of interest

The Victorian Government requires its Evaluation Panel members to act in an ethical manner, declare conflicts of interest and withdraw from considering applications where such conflict exists.



Proposed key dates for the Victorian Cancer Survivorship Program: Pilot Projects are indicated in the table below.

Survivorship grant process opens	Thursday 21 April 2011
Deadline for registration for information session	Friday 20 May 2011
Submission of questions for information session	Friday 20 May 2011
Question and answer session for applicants	Friday 27 May 2011
Closing date for applications	Monday 27 June 2011
Applicants informed of outcome	From 25 July 2011

## 9. Question and answer session

The question and answer session is mandatory for applicants/project representatives.

11.00 am Friday 27 May 2011

Department of Health Room 1.01, Level 1 50 Lonsdale Street MELBOURNE VIC 3000

You must register to attend this session and obtain a security pass

A question and answer session will be held to give applicants an opportunity to hear an overview of the aims and objectives of the Program. It is also an opportunity for applicants to have any questions answered relating to the aims and objectives of the grant process, or the application process. Attendance is a mandatory requirement for applicants. If the lead applicant is unable to attend, another representative with a direct interest in the project and who is named in the application must attend.



Applications submitted whereby the applicant or a representative has not attended the question and answer session will be deemed ineligible.

The department would like all questions forwarded prior to the session, by **Friday 20 May 2011** to allow time for the department to form responses.

Please register for the session with Tania Wohling, Project Support Officer, Cancer Strategy & Development, by Friday 20 May 2011. Registered attendees will need to obtain a security access card from Department of Health reception before making your way to Level 1.

Email: Tania.Wohling@health.vic.gov.au

Telephone: 03 9096 2081

# 10. Submission of applications

The question and answer session is mandatory for applicants/project representatives.

All applicants must complete a Victorian Cancer Survivorship Program: Pilot Projects application form.

Please provide one (1) electronic copy application.

The department will NOT accept faxed or hard copies of applications.

Please forward electronic applications in word format to:

Tania Wohling, Project Support Cancer Strategy & Development

Email: Tania.Wohling@health.vic.gov.au

Telephone: 03 9096 2081

Signatures: Electronic signatures are accepted.

Applications will be accepted if they are emailed on or before the closing date.

Applications must be received by 2 pm, Monday 27 June 2011

Please note incomplete or late applications will not be accepted

# APPENDIX 1 Administration and reporting requirements for Department of Health funding

#### 1. Applicant

The Applicant will be responsible for guiding and managing the project through to completion. This will include liaising with collaborators and coordinating reporting requirements of the grant with the administering organisation.

Where the project involves several sites, the Applicant must obtain written commitment from all Heads of Departments of collaborative partners not within the Administering Organisation or Host Organisation, and must assume responsibility for undertaking and completing the activities outlined in the application.

#### 2. Administering organisation

The Administering Organisation will be responsible for administration of the project and funding.

Funds must only be used for the purposes set out in the agreement.

#### 3. Goods and services tax

GST will be paid on top of grant amounts where appropriate. This will be determined by the administering organisation's GST status. This status must be identified by the financial delegate of the Administering Organisation. Please include the administering organisation's GST status in the application.

#### 4. Reporting

Funding recipients will be required to submit reports on a regular basis.

The reporting schedule is outlined in the following table.

Report	Reporting frequency	Due	
Project plan	Once	Within 3 months	
Progress against milestones and/or targets	6-monthly	Every 6 months from receipt of funds	
Financial reports (to be included in progress report)	Annually	Every 12 months from receipt of funds	
Final report	Once only	Within 4 months post completion of funding	
Ad hoc reports	As requested by the department	On request with a negotiable time frame not greater than six weeks	

These reports will enable the department to assess whether the project is proceeding satisfactorily, and that funds are being acquitted in accordance with the original application goals.

The department reserves the right to consider suspending funding if progress is considered unsatisfactory, or funds have not been utilised in accordance with the grants process, and project's aims and objectives.

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# Appendix 3: Evidence from the literature

Despite limited evidence-based guidance, key components of survivorship care have been proposed. The United States Institute of Medicine defines the essential elements of survivorship care as: prevention and surveillance for recurrent and new cancers and late effects; intervention to address the consequences of cancer and cancer treatments; and coordination between specialists and primary care providers to enable survivors' health needs to be met (Hewitt, Greenfield & Stovall 2006).

Providing follow-up care in the community has been found to be acceptable and safe with some survivor populations in defined circumstances (Jefford et al. 2013).

In the United Kingdom (UK), the importance of developing risk-stratified pathways of care has been highlighted. Identified risk-stratified pathways include supported self-management, shared care and complex case management (Macmillan Cancer Support 2013). Stratifying survivors according to risks and needs better targets resources and interventions to survivors' individual needs. Macmillan Cancer Support has employed 'big data' analysis to better map cancer survivorship across tumour streams in recognition of the need to develop more evidence to guide risk stratification (Macmillan Cancer Support 2014). Further research is required to guide risk stratification pathway development.

Needs assessments (patient-reported outcome measures) are considered an important component of risk stratification and cancer follow-up (Watson et al. 2012). They are associated with improved symptom control, increased supportive care referrals and patient satisfaction (Kotronoulas et al. 2014). They enable appropriate and timely targeting of resources (National Cancer Action Team 2011).

Survivorship care plans (SCPs) are widely advocated as key communication tools in survivorship care and appear to have face value, despite limited evidence. Parry et al. (2013) highlight the lack of evidence and agreed metrics to define the impact of SCPs on survivor outcomes and care delivery. They note that SCPs are communication tools and that their impact needs to be considered in the context of the wider care planning intervention. They also recommend that 'studies documenting the organisational context and factors that promote or inhibit efficacious survivorship care planning are needed' (Parry et al. 2013, p. 2).

It is important to understand the impact and influence socio-cultural diversity may have on survivorship care planning (Parry et al. 2013). Different conceptions of cancer may be traditionally held by various members of culturally diverse communities. Beliefs impact on participation in screening, engagement in risk behaviours, information-seeking behaviour and decision making (Australian Government Federation of Ethnic Communities Councils of Australia 2010).

Nurse-led models of post-treatment follow-up of adult cancer survivors have demonstrated no difference in survival rates or in detection of cancer recurrence (Howell et al. 2012). There is increasing evidence regarding the outcomes of nurse-led services compared with traditional models. Gates and Krishnasamy (2009) report the following outcomes from the literature:

- increased referrals and partnership with support services
- increased satisfaction with follow-up care
- delivery of tailored care through flexible delivery approaches
- increased capacity to facilitate behavioural change through timing interventions at teachable moments
- tailored self-management approaches reduce patient-reported physical problems.

Development and implementation of new models of care need to be considered in the context of processes that underpin sustained delivery of new models of care. In the UK, the National Health Service delivery and organisation program caution that:

... evidence on implementation and sustainability of innovations is particularly complex, and is difficult to disentangle from that on change management and organisational development. The evidence ... suggests a messy model of assimilation, in which organisations move back and forth between initiation, development, and implementation, punctuated variously by shocks, setbacks and surprises. Success in implementing and sustaining an innovation in service delivery and organisation depends on many ... factors.

(National Institute for Health Management 2004, p.4)

# Appendix 4: Outline of VCSP pilot projects

Breast Cancer projec	pt .
Delivery mechanism	Established new nurse-led face-to face or telephone consultation     Added to existing breast care nurse role
Risk stratification	<ul> <li>Survivors of early breast cancer risk stratified to shared care at MDM</li> <li>Risk stratified to face-to-face/phone consultation with nurse</li> </ul>
Intervention and delivery	<ul> <li>Nurse-led clinic (NLC) scheduled six to 12 months post-diagnosis</li> <li>Survivors complete screening tools prior to NLC</li> <li>Supportive care screening included</li> <li>Follow-up care plan developed and signed by breast care nurse and surgeon, then mailed to the survivor and GP with the shared care agreement</li> <li>Alternate follow-up between GP and cancer specialist as per plan</li> <li>Survivors encouraged to book a long appointment with the GP</li> <li>Process for rapid access back to acute system</li> </ul>
Referrals	<ul><li>Routine referral to BreaCan</li><li>Menopause after cancer clinic and other services as per needs assessment</li></ul>
Tools developed to support model	<ul> <li>Treatment plan template including follow-up care plan</li> <li>NLC checklist</li> <li>Adapted and translated supportive care screening tools (Arabic, Chinese, Greek, Italian, Turkish and Vietnamese)</li> <li>Template letters for GPs and survivors</li> <li>GP shared care agreement</li> <li>BreaCan Navigator tool for survivors (web and app)</li> <li>Survivorship care planning tools</li> <li>Online referral tool for BreaCan</li> <li>Guidelines on breast cancer care (to be published)</li> </ul>

Barwon South West	Barwon South West Survivorship Project					
Delivery mechanism	<ul> <li>Established new NLC separate to other clinic appointments, although initial consultation may occur at an established cancer specialist clinic</li> <li>Established new nursing role in regional and rural centres</li> <li>0.6 EFT regional and 0.2 EFT rural</li> </ul>					
Risk stratification	Cancer specialist remained responsible for determining risks and level of follow up care (specialist/shared/GP led)					
Intervention and delivery	<ul> <li>Oncologist and nurse identified survivors towards the end of treatment</li> <li>Cancer specialists referred survivors</li> <li>Two face-to-face nurse consultations provided</li> <li>First consultation: assessment and screening tools completed</li> <li>Survivorship care plan (SCP) developed, signed by specialist, GP telephoned</li> <li>Second consultation: SCP intervention including education, information provision and care coordination</li> </ul>					
Referrals	Relevant community-based referrals based on needs assessment (large number of allied health referrals)					
Tools developed to support model	<ul> <li>Tumour-specific SCPs</li> <li>GP surveillance schedules for each tumour type</li> <li>Introduction letter for GP and primary healthcare nurse</li> <li>Survivorship service flyer</li> <li>Radiation late effects report</li> <li>General health assessment tool</li> </ul>					

Melanoma project	
Delivery mechanism	<ul><li>Within existing clinic</li><li>No NLC developed</li><li>Did not require alteration of workforce roles</li></ul>
Risk stratification	Victorian melanoma clinicians individually determined suitability for discharge to GP follow-up based on risks and needs
Intervention and delivery	<ul> <li>Single consultation: clinicians provided survivor with diary-based SCP</li> <li>Mechanism to self-screen for supportive care needs trialled</li> <li>Low-risk survivors were discharged to GP follow-up</li> <li>Higher risk survivors remained with cancer specialist care or alternated care with GP</li> <li>Letter sent to GP indicating stage, prognosis, risk stratification factors and surveillance plan</li> <li>Process for rapid access back to acute system</li> </ul>
Referrals	Not reported
Tools developed to support model	<ul> <li>GP discharge letter template</li> <li>Personal melanoma diary containing a summary of the information provided to the patient during acute care, surveillance plan, supportive care screening and education regarding skin examination</li> <li>Risk-stratified shared care treatment and surveillance pathways</li> <li>SMS prompts for skin self-examination and supportive care screening</li> </ul>

AYA project	
Delivery mechanism	<ul> <li>New care coordination appointments delivered within existing allied health and nursing roles</li> <li>Usually delivered alongside existing hospital appointments across three sites</li> <li>Rural/interstate survivors could receive phone/email follow-up</li> </ul>
Risk stratification	<ul> <li>AYA survivors assessed as a higher risk group (cancer specialist follow-up indicated)</li> <li>Developed intervention levels for survivors with varied levels of need</li> </ul>
Intervention and delivery	<ul> <li>Initial face-to-face consultation with care coordinator two weeks before the end of treatment: supportive care screening, GP linkage, SCP generated</li> <li>Second consultation about two weeks later: discussed SCP, promoted self-management, health promotion</li> <li>Endorsed plan, provided hard copy and electronic copy to GP</li> <li>Survivors saw GP four weeks post-treatment to discuss SCP</li> <li>Review appointments with care coordinators at three, six, nine and 12 months post-treatment</li> </ul>
Referrals	Large numbers of referrals to educational, vocational, exercise physiology, psychology and allied health services (identified through needs assessment)
Tools developed to support model	<ul> <li>Amended version of AYA Survivorship Screening Tool (for validation)</li> <li>Fact sheets/resources for young people: <ul> <li>Finding and visiting a GP</li> <li>a directory of youth-friendly GPs in Victoria and Tasmania</li> <li>Information and resources for young people</li> <li>survivorship AYA resource in development (print and online versions and app)</li> </ul> </li> <li>GP resources <ul> <li>Cancer care for adolescents and young adults: Resources for GPs</li> </ul> </li> </ul>

Moving Forward with	Moving Forward with Confidence project				
Delivery mechanism	<ul> <li>Added new face-to-face nurse consultation (within existing roles) across four sites</li> <li>Participating services:         <ul> <li>oncology rehabilitation program</li> <li>Breast Cancer Transitions (psycho-educational) Program</li> <li>haematology service follow-up appointment</li> <li>colorectal service post-treatment review (trialled)</li> </ul> </li> <li>Helpline nurses reviewed SCPs</li> </ul>				
Risk stratification	Not applied				
Intervention and delivery	<ul> <li>SCPs developed with nurse – usually at the health service</li> <li>Helpline nurse reviews SCPs at one, four and eight months</li> <li>Motivational interviewing techniques used to support wellbeing goals</li> <li>Supportive care screening at baseline and four-month follow-up</li> <li>SCP and plan updates shared with survivors, GPs, helpline and health services</li> </ul>				
Referrals	As identified through needs assessment and follow-up calls (psychology, mindfulness meditation and allied health services)				
Tools developed to support model	<ul> <li>My health and wellbeing plan (adapted from SCP developed by Queensland University of Technology) – the plan aimed to provide structure for a self-efficacy directed conversation using motivational interviewing techniques</li> <li>Information pack provided including existing resources (Life after cancer booklet, Just take it day to day DVD)</li> <li>Guide to local and regional allied health, counselling and peer support services provided to nurses</li> </ul>				

Positive Change for	Life project
Delivery mechanism	<ul> <li>Late effects clinic setting</li> <li>Dietitian was employed 0.1 EFT</li> <li>Partnership with community fitness centres</li> </ul>
Risk stratification	Survivors of stem cell transplantation for haematological cancers considered at high risk for late effects
Intervention and delivery	<ul> <li>12-month program</li> <li>Dietician intervention based on the Coach for Heart Health model</li> <li>Face-to-face consultation at enrolment and 12 months</li> <li>Coaching phone calls at two weeks, four months and eight months</li> <li>Individualised physical activity plan – community-based delivery (gym, yoga, etc.)</li> <li>Additional group physical activity events</li> <li>Hospital-based reviews (impact of/progress with physical activity)</li> <li>Survivors encouraged to discuss program with GPs</li> </ul>
Referrals	To community-based dietitian/exercise physiologist where required
Tools developed to support model	<ul> <li>Participant handbook developed including nutrition component for transplant survivors, three-day food diary, weekly meal planner and weekly shopping list</li> <li>Incentive strategies – promotional items</li> <li>Monthly newsletters distributed to participants and to GPs</li> <li>GP packs containing clinic letter, project information flyer project letter and a copy of the SCP</li> </ul>

# Appendix 5: Measures

#### AQoL-6D (The Assessment Quality of Life-Adolescent)

The AQoL-6D is a multi-attribute utility instrument that assesses quality of life with the use of 20 items in six domains including independent living, relationships, mental health, coping, pain and senses. It is validated for use with adolescents in healthcare settings (Hawthorne 2006; Richardson et al. 2004).

#### AQoL-8D (Assessment of Quality of Life 8D)

The AQoL-8D is a 35-item instrument with eight dimensions (independent living, pain, senses, relationships, mental health, coping, happiness and self-worth) that may also be combined into two 'super dimensions' for mental and physical health (Richardson et al. 2011).

#### Assessment of self-efficacy in managing cancer symptoms and treatment side effects

Subscales of the assessment of self-efficacy in managing cancer symptoms and treatment side effects scale are referred to in this report (Campbell et al. 1998). The first section comprises items that assess both generalised strategies for coping with a cancer diagnosis and the challenges it presents. The second section comprises items that assess specific self-care strategies. Part A assesses frequency of use of strategies on a scale of 1 to 4 (1 = not at all and 4 = a great deal) and Part B assesses confidence/perception of having dealt well with the situation on a scale of 1 to 10 (1 = not confident at all and 10 = extremely confident) (Campbell et al. 2008).

#### BARSE (Barriers Specific - Self-Efficacy Scale)

This scale is designed to capture individuals' perceived capabilities to exercise three times per week for 40 minutes over a two-month period in the face of commonly identified barriers. For each item, individuals indicate their confidence to execute the behaviour on a 100-point percentage scale comprised of 10 increments ranging from 0% (not at all confident) to 100% (highly confident) (McAuley 1992).

#### DT (Distress thermometer and problem list - NCCN)

The DT was originally devised in the United States as a quick tool for assessing a patient's level of distress. It was subsequently expanded to include a problem checklist that has since been revised for use within a UK setting. Although originally conceived as a holistic screening tool to prompt referrals to appropriate health professionals, the DT has been further developed in Bristol to address more directly the patient's needs in a timely fashion. Aims of the *Distress thermometer and problem list* are to provide a brief holistic (bio-psycho-social-spiritual) assessment of patients' concerns as they move through their cancer treatment. It also aims to document the patient's: physical state and experience of treatment side effects (pain, nausea, fatigue, etc.); psychological and emotional wellbeing as well as any interpersonal concerns (anxiety/fear, depression/unhappiness, relationship, sexual or family concerns, etc.); social/practical concerns (housing, finances, need for information, etc.); and existential concerns (spiritual crisis, life regrets, etc.) and to identify services and resources that may help to resolve the patient's concerns (Brennan et al. 2012).

#### FACIT-Fatigue (Functional Assessment of Chronic Illness Therapy-Fatigue) scale

This is a 13-item, symptom-specific subscale of the FACT scales with demonstrated reliability and validity. It assesses self-reported fatigue and its impact upon daily activities and function. The FACIT-Fatigue scale is formulated for self-administration and uses a five-point Likert scale with a recall period for each question of 'during the past 7 days' (FACIT.org 2010).

#### FACT-B (Functional Assessment of Cancer Therapy-Breast)

The FACT-B is a 44-item self-report instrument designed to measure multidimensional quality of life (QL) in patients with breast cancer. It consists of the FACT-General (FACT-G) and the Breast Cancer Subscale (BCS), which complements the general scale with items specific to QL in breast cancer. The FACT-B was developed with an emphasis on patients' values and brevity and is available in nine languages (Brady et al. 1997).

#### FACT-BMT (Functional Assessment of Cancer Therapy-Bone Marrow Transplant)

This is a self-administered tool used to assess multidimensional domains of quality of life in patients after stem cell transplantation. It consists of the FACT-General (FACT-G) and a specific bone marrow transplantation subscale covering additional concerns related to treatment. It covers 37 items over the domains of physical, social, emotional and functional wellbeing as well as a transplant-specific scale (McQuellon et al. 1997).

#### General health questionnaire (not validated)

#### Godin Leisure Time Physical Activity Questionnaire (GLTEQ)

This is a brief four-item survey assessing self-reported leisure time physical activity over the previous seven days. The score is expressed in units. Weekly frequencies of strenuous, moderate and mild activities are multiplied by nine, five and three respectively, with the derived values corresponding to metabolic equivalent of task (MET) value categories of the activities listed. A final weekly activity score is computed. The frequency of strenuous and moderate activity has been used to compute a health contribution score (Godin, Jobin & Bouillon 1986; Godin & Shephard 1985).

#### HeiQ (Health Education Impact Questionnaire)

The HeiQ was developed to assess satisfaction with chronic disease self-management programs and advance the process of quantifying, understanding and defining the impact of programs on participants' physical and mental health and health-related attitudes and behaviours. It consists of 51 questions, organised into a set of eight scales: positive and active engagement in life; health-directed behaviour; skill and technique acquisition; constructive attitudes and approaches; self-monitoring and insight; health services navigation; social integration and support; and emotional wellbeing (reversed scale). The HeiQ provides a broad profile of the potential impacts of patient education programs (Osborne, Elsworth & Whitfield 2007).

#### HeLMS (Health Literacy Management Scale Version 1.1)

The HeLMS is a measure of an individual's capacity to seek, understand and use health information within the healthcare setting. There are 29 items and eight distinct scales: five focus on individuals' abilities to seek, understand and utilise health literacy and three focus on broader factors that affect abilities. Scored on a five-point Likert scale (1 = unable to do and 5 = can do without difficulty), the focus is on difficulty experienced (Jordan et al. 2013).

#### **HLQ** (Health Literacy Questionnaire)

The HLQ is a comprehensive measure of health literacy. It is available in languages other than English and consists of nine domains: feeling understood and supported by healthcare providers; having sufficient information to manage my health; actively managing my health; social support for health; appraisal of health information; ability to actively engagement with healthcare providers; navigating the healthcare system; ability to find good health information; and understanding health information well enough to know what to do. It is patient-centred, assesses an individual's health literacy and provides detailed information about what needs to be done to improve systems and services (Osborne et al. 2013).

#### MRS (Menopause Rating Scale)

The MRS is a health-related quality-of-life scale developed in the early 1990s. The self-reported scale was designed to measure health-related quality of life (QoL) or severity of complaints in ageing women, to measure changes over time and across different cultures. It comprises 11 symptoms, each rated on a five-point scale of severity. It is available in 25 languages (Dinger et al. 2006; Schneider et al. 2000).

#### PEQ (Patient Experience Questionnaire)

This short questionnaire incorporates 18 items across five domains that assess short-term outcomes, communication experiences, communication barriers, relations with auxiliary staff and emotions. It emphasises what patients value the most (interaction, emotions and outcome) and may represent a valuable tool for doctors who want feedback from their patients on the function of their doctor–patient relationships (Steine, Finet & Laerum 2001).

#### **REAP (Rapid Eating Assessment for Patients)**

The REAP is a short questionnaire designed to quickly assess the dietary and eating habits of patients, particularly in a low-literacy population. It can be used to identify which patients would benefit most from further dietary/nutritional counselling (Gans et al. 2006).

#### SF-12 (Short Form 12 health-related burden of disease)

The SF-12 is a multipurpose health survey which yields a profile of health-related burden of disease as well as physical and mental scores. The SF-12 is validated for use with individuals aged 14 years or older (Ware, Kosinski & Keller 1994).



Project and PROM timeframes	Breast Cancer project	Barwon South West Survivorship project	Melanoma project	AYA project	Moving Forward with Confidence project	Positive Change for Life project
Baseline	DT and problem list MRS FACT-B	DT and problem list HLQ AQoL 8D HeiQ General health questionnaire (not validated)		AYA Survivorship Screening Tool (not validated) AQoL-6D SF-12	DT and problem list HeiQ HeLMs Subscales of assessment of self-efficacy in managing cancer symptoms, treatment side effects	FACT-BMT BARSE GLTEQ REAP FACIT
1 week		HLQ AQoL 8D HeiQ				
3 months		HLQ AQoL 8D HeiQ	Prompted to complete DT and problem list through SMS/email	AQoL-6D SF-12		
4 months					DT and problem list	
6 months			Prompted to complete DT and problem list through SMS/email	AQoL-6D	HeiQ HeLMs Subscales of assessment of self-efficacy in managing cancer symptoms and treatment side effects	FACT-BMT BARSE GLTEQ REAP FACIT
9 months			Prompted to complete DT and problem list through SMS/email			

Project and PROM timeframes	Breast Cancer project	Barwon South West Survivorship project	Melanoma project	AYA project	Moving Forward with Confidence project	Positive Change for Life project
12 months			Prompted to complete DT and problem list through SMS/email			FACT-BMT BARSE GLTEQ REAP FACIT
18 months						FACT-BMT BARSE GLTEQ REAP FACIT



# Appendix 7: Survivorship care plan elements

Project names and features in SCP development	Breast Cancer project	Barwon South West Survivorship project	Melanoma project	AYA project	Moving Forward with Confidence project	Positive Change for Life project
Format: paper-based	V	V	(diary format)	~	V	<b>~</b>
Format: electronic				~		
Supportive care screening baseline	V	V		V	V	
Supportive care screening at four months					~	
SMS/email prompt to screen			V			
Treatment summary front of SCP	V	V	V	~		
Treatment summary end of SCP					V	
SCP updated at key time points			V		V	
Surveillance schedule	~	In GP letter	V	~	~	
Health care professional contacts	~	V	V	~	~	
Hopes/goals		V		<b>✓</b>	V	
Recommend- ations	~	V	~	V	<b>v</b>	
Wellbeing plan	~	V	~	~	~	
Symptom diary		V				
Current medication list		V	V			

Project names and features in SCP development	Breast Cancer project	Barwon South West Survivorship project	Melanoma project	AYA project	Moving Forward with Confidence project	Positive Change for Life project
Referrals listed	~	~				
Community resources	V	V		V	V	
Advice to visit GP	~	~			~	
Personal details			~	~		
Survivor signature		~			~	
Cancer clinician signature	~	~		V	V	



# Example of a risk-stratified pathway: GP shared care model of follow-up care for patients with early breast cancer at completion of treatment

A risk stratification model was developed whereby women diagnosed with early breast cancer including DCIS are presented at a weekly multidisciplinary team meeting. The team comprises breast surgeons, radiation oncologists, medical oncologists, radiologists, pathologists, breast care nurses and allied health professionals. Cases are discussed for eligibility for a nurse-led clinic (NLC) appointment at the end of definitive treatment and a shared care follow-up arrangement between the breast service and a patient-nominated GP. Decision making regarding suitability considered individual and personal factors affecting the patient as well as disease and treatment factors. If suitable, an appointment is arranged for the woman (and carer) to attend an NLC scheduled at the end of definitive treatment. There is a risk stratification pathway to determine whether the NLC is delivered face to face or via telephone. Survivors could also elect to access the NLC by telephone if they preferred this option.

Formal shared care agreements between the breast service and the nominated GP were attempted to ensure GP engagement and decrease the likelihood that survivors would be lost to follow-up. Timely, appropriate communication between healthcare sectors, clarified pathways of care, identified roles and responsibilities for follow-up and rapid re-access provision have been instrumental in providing quality clinical follow-up in the primary setting and in ensuring a smooth transition back into the acute system if required.

See diagram on the following page.

#### Breast service pilot model diagram

# Active treatment for breast cancer

End of treatment: outpatient medical consultation and mammogram

#### 6-12 months post-diagnosis:

#### Screening tools completed:

- Distress Thermometer and Problem List
- FACT-B
- Menopause Rating Scale

Attends nurse-led clinic

Follow-up care plan developed in consultation with participant (informed by risk stratification and screening tool outcomes)

# Shared care between GP and breast service

Appointments alternate (as outlined in care plan)

Care plan signed off by breast surgeon and breast care nurse

Sent to participant and nominated GP

#### Years 1-2 Breast cancer follow-up

- History and clinical examination every 3–6 months; investigations ordered and examinations performed at appointments by the clinician
- Breast imaging (mammogram) every
   12 months at the treating breast service
- Other investigations performed as required such as bone density

#### Years 3-5 Breast cancer follow-up

- History and clinical examination every 6–12 months; investigations ordered and examinations performed at appointments
- Breast imaging (mammogram) every
   12 months at treating breast service
- Other investigations ordered as required.

#### After 5 years Breast cancer follow-up

- History and examination annually: investigations ordered and examinations performed at appointments
- Breast imaging (mammogram) every 12 months at treating breast service or locally (organised by GP)
- Other investigations ordered as required.



The Positive Change for Life project assisted survivors to self-manage their diet and physical activity levels through a 12-month program. The project was implemented alongside an existing late effects service. The intervention aimed to help ameliorate late effects risks and achieve a number of positive wellbeing outcomes. All 53 (RR 100%) participants completed baseline assessments. The majority (36/53; 68%) of participants were overweight/obese at the beginning of the project.

#### Positive Change for Life project outcomes

Self-reported outcomes	6 months n = 41/51, 80% RR	12 months n = 38/50, 76% RR**	18 months n = 15, 65% RR** *
Fatigue			
Improved fatigue	32%	37%	27%
Nutrition			
Improved nutrition scores	61%	82%	87%
Reduced unhealthy eating habits	56%	68%	87%
Physical activity			
Improved physical activity levels	78%	76%	87%
Quality of life			
Improved physical wellbeing	27%	18%	20%
Improved emotional wellbeing	27%	26%	33%
Improved functional wellbeing	32%	42%	40%
Improved overall quality of life	25%	32%	47%
Qualitative			
Continue nutrition changes after project?		96%	
Continue exercise program after project?		89%	
Carers observed benefit to participant		94%	
Carer personally benefited		85%	
Measured outcomes		12 months	
Weight loss		75%	
Reduced waist circumference		75%	
Reduced hip circumference		53%	
Improved waist:hip ratio		67%	
Improved systolic blood pressure		53%	
Improved diastolic blood pressure		58%	

Measured outcomes	12 months		
Improved total cholesterol*	69%		
Improved HDL-cholesterol*	64%		
Improved LDL-cholesterol*	56%		
Improved triglycerides*	57%		
Improved fasting blood glucose*	50%		

<sup>\*</sup> participants with abnormal values at baseline

<sup>\*\*3</sup> patients withdrawn (W/D) not included
\*\*\* some participants did not complete an 18-month follow-up at the time of reporting



Domain	Recommendation		
Expanded survivorship community of practice forums	Expand the forums to disseminate project teams' knowledge and experiences to funders, implementers and evaluators.		
Workforce capability planning framework	Use/adapt existing workforce capability planning frameworks to ensure future initiatives optimally integrate workforce, service and financial planning for delivering models of follow-up care across the acute-primary health interface.		
	Collect data on the profile of the cancer survivorship workforce as part of reporting of future cancer survivorship initiatives.		
Primary-care-driven transformative change management approach	Consider adopting a primary-care-driven transformative change management approach, supported by statewide, local primary care organisations and local GP liaison units to enable the adoption, implementation and sustained use of new models of follow-up care.		
	Consider reframing and advocating that cancer survivorship be framed within a chronic disease management model in future cancer initiatives. Chronic disease management software used in primary care may provide an existing platform for survivorship care planning.		
Research-driven cancer survivorship initiative	Consider a multi-project comparative health systems research approach to understand common factors influencing the success of various survivorship models and strategies.		
	Consider providing additional resources to VCSP projects to enable longitudinal data to be collected.		
	Consider using a process evaluation lens. For example, to what extent can activity-based funding and health pathways be modified to support shared care models and what alternative workforce models can support shared care for cancer survivors?		

# Glossary

Health literacy: 'Health literacy is the knowledge and skills needed to understand and use information relating to health issues such as drugs and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies and staying healthy'.' (Australian Bureau of Statistics 2009)

Needs assessment: Holistic needs assessment considers all aspects of a person's needs and seeks to understand them as a whole. Undertaking a holistic needs assessment is not an end in itself. It is a means of ensuring that the person's concerns or problems are identified so that attempts can be made to address them. It supports the broader aim of ensuring personalised care that reflects an individual's health and care needs. An assessment should always result in a care or action plan (National Cancer Action Team 2011).

Nurse-led clinics: There are a variety of definitions for nurse-led clinics (NLCs). They are characterised by the delivery of evidence-based care, focused on patient-centred outcomes and delivered by advanced practice nurses (Gates & Krishnasamy 2009). Nurses work autonomously and mostly have their own caseload (Queensland Health 2013). The NLCs in these projects incorporated supportive needs assessment, education and care coordination. Post-treatment care plans were developed in collaboration with survivors.

Partnerships with community organisations: In this report, this refers specifically to collaborations between health services and cancer-related non-government organisations or community health and fitness organisations.

Rapid re-access: Process whereby survivors who have transitioned to shared care or discharge to GP follow-up can access an urgent review from a cancer specialist (for example, in cases of suspected recurrence or new concerns requiring a specialist review).

Risk stratification: 'Stratified means that the clinical team and the person living with cancer make a decision about the best form of aftercare based on their knowledge of the disease (what type of cancer and what is likely to happen next), the treatment (what the effects or consequences may be both in the short term and long term) and the person (whether they have other illnesses or conditions, and how much support that they feel they need)' (Macmillan Cancer Support 2013). Risk stratification pathways identify subgroups of survivors with differing levels of needs and inform follow-up care.

Self-management: Can be defined as 'awareness and active participation by the person in their recovery, recuperation, and rehabilitation, to minimise the consequences of treatment and promote survival, health and well-being' (Davies & Batehup 2010, p. 6).

Self-management support: 'What health and social care professionals, and service delivery organisations do to support self-management' (Davies & Batehup 2010, p. 6).

Shared care: 'Shared care refers to the care of a patient that is shared by two or more clinicians of different specialties (or systems that are separated by some boundaries)' (Oeffinger & McCabe 2006, p. 5118). In this report, shared care refers to partnerships between cancer specialists and GPs.

Survivor: an individual is considered a cancer survivor from the time of cancer diagnosis through the balance of his or her life (Hewitt et al 2006)

Survivorship care: survivorship care is a distinct phase of care for cancer survivors. It includes four components: (1) prevention and detection of new cancers and recurrent cancer; (2) surveillance for cancer spread, recurrence, or second cancers; (3) intervention for consequences of cancer and its treatment; and (4) coordination between specialists and primary care providers to ensure that all of the survivor's health needs are met. (Hewitt et al 2006)

Survivorship care plan (SCP): 'Formal, written documents that provide details of a person's cancer diagnosis and treatment, potential late and long-term effects arising from the cancer and its treatment, recommended follow-up, and strategies to remain well' (Australian Cancer Survivorship Centre 2014).

## References

Australian Bureau of Statistics 2014, *Australian demographic statistics March 2014*, cat. no. 3101.0, ABS, viewed 25 September 2014, <a href="http://www.abs.gov.au/ausstats/abs@.nsf/mf/3101.0">http://www.abs.gov.au/ausstats/abs@.nsf/mf/3101.0</a>.

Australian Bureau of Statistics 2014, *Australian social trends June 2009*, cat. no. 4102.0, ABS, viewed 27 May 2015, <a href="http://www.abs.gov.au/ausstats/abs@.nsf/mf/3101.0">http://www.abs.gov.au/ausstats/abs@.nsf/mf/3101.0</a>.

Australian Cancer Survivorship Centre 2014, Survivorship care planning, Australian Cancer Survivorship Centre, viewed 22 May 2014, <a href="http://petermac.komodocms.com/cancersurvivorship/SurvivorshipCarePlanning">http://petermac.komodocms.com/cancersurvivorship/SurvivorshipCarePlanning</a>.

Australian Government Department of Health 2014, *Chronic disease management patient information*, Australian Government, viewed 18 September 2014, <a href="http://www.health.gov.au/internet/main/publishing.nsf/content/mbsprimarycare-chronicdisease-pdf-infosheet">http://www.health.gov.au/internet/main/publishing.nsf/content/mbsprimarycare-chronicdisease-pdf-infosheet</a>.

Australian Government Federation of Ethnic Communities Councils of Australia 2010, *Cancer and culturally and linguistically diverse communities*, Australian Government, viewed 7 August 2014, <a href="http://www.fecca.org.au/images/stories/pdfs/cancer\_cald\_communities\_report2010.pdf">http://www.fecca.org.au/images/stories/pdfs/cancer\_cald\_communities\_report2010.pdf</a>>.

Baker D 2006, 'The meaning and the measure of health literacy', *Journal of General Internal Medicine*, vol. 21, pp. 878–883.

Blanch-Hartigan D, Forsythe L, Alfano C, Smith T, Nekhlyudov L, Ganz P, Rowland J 2012, 'Provision and discussion of survivorship care plans among cancer survivors: results of a nationally representative survey of oncologists and primary care physicians', *Journal of Clinical Oncology*, vol. 20, no. 32, pp. 1578–1585.

Booth M, Knox S, Kang, M 2008, 'Encounters between adolescents and general practice in Australia', *Journal of Paediatrics and Child Health*, vol. 44, no. 12, pp. 699–705.

Brady M, Cella D, Mo F, Bonomi A, Tulsky D, Lloyd S, Deasy S, Cobleigh M, Shiomoto G 1997, 'Reliability and validity of the Functional Assessment of Cancer Therapy-Breast quality-of-life instrument', *Journal of Clinical Oncology*, vol. 15, no. 3, pp. 974–986.

Brennan J, Gingell P, Brant H, Hollingworth W 2012, 'Refinement of the distress management problem list as the basis for a holistic therapeutic conversation among UK patients with cancer', *Psycho-Oncology*, vol. 21, no. 12, pp. 1346–1356.

Campbell J et al. 1998, 'Development of a scale to assess cancer patients' self-efficacy with managing symptoms and treatment side effects' (No. RAN9728), Queensland Nursing Council and Glaxo Wellcome Australia, Brisbane.

Campbell J, Yates P, Clinton M, Mirolo B, Sellick K 2008, 'Cancer self-efficacy', Report to the Queensland Nursing Council.

Cancer Council Victoria 2014, *Cancer survival increase: 1 in 25 Victorians have had cancer*, viewed 25 September 2014, <a href="http://www.cancervic.org.au/about/media-releases/2014-media-releases/2014-media-releases/2014/mr-cancer-survival-increase.html">http://www.cancervic.org.au/about/media-releases/2014-media-releases/2014-media-releases/2014-media-releases/2014-media-releases/2014/mr-cancer-survival-increase.html</a>>.

Davies N, Batehup L 2010, 'Self-management support for cancer survivors: guidance for developing interventions: an update of the evidence', National Cancer Survivorship Initiative Supported Self-Management Workstream, Macmillan Cancer Support, viewed 18 September 2014, <a href="http://www.ncsi.org.uk/wp-content/uploads/Guidance-for-Developing-Cancer-Specific-Self-Management-Programmes.pdf">http://www.ncsi.org.uk/wp-content/uploads/Guidance-for-Developing-Cancer-Specific-Self-Management-Programmes.pdf</a>.

Davies N, Thomas R, Batehup L 2010, 'Advising cancer survivors about lifestyle: a selective review of the evidence', National Cancer Survivorship Initiative Supported Self-Management Workstream, Macmillan Cancer Support, viewed 18 September 2014, <a href="http://www.ncsi.org.uk/resources/ncsi-reports/">http://www.ncsi.org.uk/resources/ncsi-reports/</a>>.

Demark-Wahnefried W, Aziz NM, Rowland JH, Pinto BM 2005, 'Riding the crest of the teachable moment: promoting long-term health after the diagnosis of cancer', *Journal of Clinical Oncology*, vol. 23, no. 24, pp. 5814–5830.

Department of Health 2008, *Victoria's cancer action plan 2008–2011*, Cancer Strategy and Development, State Government of Victoria, Melbourne.

Dinger J, Zimmermann T, Heinemann L, Stoehr D 2006, 'Quality of life and hormone use: new validation results of MRS scale', *Health and Quality of Life Outcomes*, vol. 4, pp. 32–36, viewed 18 September 2014, <a href="https://www.hglo.com/content/4/1/32">www.hglo.com/content/4/1/32</a>>.

FACIT.org 2010, FACIT Functional Assessment of Chronic Illness Therapy, viewed 27 August 2014, <a href="http://www.facit.org/">http://www.facit.org/</a>.

Gans K, Risica P, Wylie-Rosett J, Ross E, Strolla L, McMurray J, Eaton C 2006, 'Development and evaluation of the nutrition component of the Rapid Eating and Activity Assessment for Patients (REAP): a new tool for primary care providers', *Journal of Nutrition Education and Behaviour*, vol. 38, no. 5, pp. 286–292.

Gates P, Krishnasamy M 2009, Nurse-led survivorship care, *Cancer Forum*, vol. 33, no. 3, viewed 18 September 2014, <a href="http://www.cancerforum.org.au/File/2009/November/CF09Nov\_175-178.pdf">http://www.cancerforum.org.au/File/2009/November/CF09Nov\_175-178.pdf</a>>.

Godin G, Shephard R 1985, 'A simple method to assess exercise behaviour in the community', *Canadian Journal of Applied Sport Science*, vol. 10, no. 3, pp.141–146.

Godin G, Jobin J, Bouillon J 1986, 'Assessment of leisure time exercise behaviour by self-report: a concurrent validity study', *Canadian Journal of Public Health*, vol. 77, no. 5, pp. 359–362.

Hawthorne G 2006, On the classification and uses of quality of life instruments, The University of Melbourne, Melbourne

Health Workforce Australia 2011, *National cancer workforce strategy: literature review*, viewed 18 September 2014, <a href="http://www.hwa.gov.au/sites/uploads/NCWS-Literature-Review.pdf">http://www.hwa.gov.au/sites/uploads/NCWS-Literature-Review.pdf</a>>.

Hewitt M, Greenfield S, Stovall E (eds) 2006, From cancer patient to cancer survivor: lost in transition, Institute of Medicine and National Research Council of the National Academies, National Academies Press, Washington DC.

Howell D, Hack T, Oliver T, Chulak T, Mayo S, Aubin M, Chasen M, Earle C, Friedman A, Green E, Jones G, Jones J, Parkinson M, Payeur N, Sabiston C, Sinclair S 2012, 'Models of care for post-treatment follow-up of adult cancer survivors: a systematic review and quality appraisal of the evidence', *Journal of Cancer Survivorship*, vol. 6, no. 4, pp. 359–371.

Jarrett C, Dadich A, Robards F, Bennett D 2011, 'Adolescence is difficult, some kids are difficult': general practitioner perceptions of working with young people', *Australian Journal of Primary* Health, vol. 17, no. 1, pp. 54–59.

Jefford M, Rowland J, Grunfeld E, Richards M, Maher J, Glaser A 2013, 'Implementing improved post-treatment care for cancer survivors in England, with reflections from Australia, Canada and the USA', *British Journal of Cancer*, vol.108, no. 1, pp. 14–20.

Jordan J, Buchbinder R, Briggs A, Gerald R. Elsworth G, Busija L, Batterham R, Richard H, Osborne R 2013, 'The Health Literacy Management Scale (HeLMS): a measure of an individual's capacity to seek, understand and use health information within the healthcare setting', *Patient Education and Counseling*, vol. 91, no. 2,pp. 228–235.

Kaoy K, Schofield P, Jefford M 2012, 'Importance of health literacy in oncology', *Asia Pacific Journal of Clinical Oncology*, vol. 8, no. 1, pp. 14–23.

Kotronoulas G, Kearney N, Maguire R, Harrow A, Di Domenico D, Croy S, MacGillivray S 2014, 'What is the value of the routine use of patient-reported outcome measures toward improvement of patient outcomes, processes of care, and health service outcomes in cancer care? A systematic review of controlled trials', *Journal of Clinical Oncology*, vol. 32, no. 14, pp. 1480–1501.

Lajous M, Mozaffarian D, Mozaffarian R, Schrag D, Adami, H 2010, 'Lifestyle prescriptions for cancer survivors and their communities', *Journal of Internal Medicine*, vol. 269, no 1, pp. 88–93.

Macmillan Cancer Support 2012, *Cured but at what cost? Long term consequences of cancer and its treatment,* Macmillan Cancer Support, UK Macmillan Cancer Support 2013, Stratified Pathways of Care, viewed 4 May 2014, <a href="http://www.ncsi.org.uk/what-we-are-doing/risk-stratified-pathways-of-care/">http://www.ncsi.org.uk/what-we-are-doing/risk-stratified-pathways-of-care/</a>.

Macmillan Cancer Support 2014, 'Routes from diagnosis: the most detailed map of cancer survivorship yet', viewed 15 July 2014, <a href="http://www.macmillan.org.uk/Documents/AboutUs/Research/Researchandevaluationreports/Routes-from-diagnosis-report.pdf">http://www.macmillan.org.uk/Documents/AboutUs/Research/Researchandevaluationreports/Routes-from-diagnosis-report.pdf</a>.

McAuley E 1992, 'The role of efficacy cognitions in the prediction of exercise behaviour in middle-aged adults', *Journal of Behavioural Medicine*, vol. 15, no. 1, pp. 65–88.

McCorkle R, Ercolano E, Lazenby M, Schulman-Green D, Schilling L, Lorig K, Wagner E 2011, 'Self-management: enabling and empowering patients living with cancer as a chronic illness', *A Cancer Journal for Clinicians*, vol. 61, no. 1, pp. 50–62.

McQuellon R, Russel G, Cella D, Craven B, Brady M, Bonomi A, Hurd D 1997, 'Quality of life measurement in bone marrow transplantation: development of the Functional Assessment of Cancer Therapy – Bone Marrow Transplant (FACT-BMT) scale', *Bone Marrow Transplantation*, vol. 19, no. 4, pp. 357–368.

Moodie M, Richardson J, Rankin B, Sinha K, Lezzi A 2009, *Predicting time trade-off health state evaluations of adolescents in four Pacific countries using the AQoL-6D instrument*, Centre for Health Economics, Monash University, Melbourne.

Naccarella L, Freijser D 2014, What makes the Cancer Survivorship Post-Treatment Care (CSPTC) workforce models of care work, for whom and in what circumstances? The Australian Health Workforce Institute Report, The University of Melbourne, Melbourne.

National Cancer Action Team 2011, Holistic needs assessment for people with cancer: a practical guide for healthcare professionals, National Health Service, viewed 18 September 2014, <a href="http://www.ncsi.org.uk/wp-content/uploads/The\_holistic\_needs\_assessment\_for\_people\_with\_cancer\_A\_practical Guide NCAT.pdf">http://www.ncsi.org.uk/wp-content/uploads/The\_holistic\_needs\_assessment\_for\_people\_with\_cancer\_A\_practical Guide NCAT.pdf</a>.

NHS Improvement 2012, Innovation to implementation: stratified pathways of care for people living with or beyond cancer – a how to guide, viewed 20 April 2014, <a href="http://www.ncsi.org.uk/wp-content/uploads/howtoguide.pdf">http://www.ncsi.org.uk/wp-content/uploads/howtoguide.pdf</a>.

National Institute for Health Management 2004, NHS Service Delivery and Organisation Research & Development Program, Briefing paper 'Spreading and sustaining innovations in health service delivery and organisation', National Institute for Health Management, viewed 18 September 2014, <a href="http://www.nets.nihr.ac.uk/programmes/hsdr">http://www.nets.nihr.ac.uk/programmes/hsdr</a>.

Oeffinger K, McCabe M 2006, 'Models for delivering survivorship care', *Journal of Clinical Oncology*, vol. 24, no. 32, pp. 5117–5124.

Osborne R, Elsworth G, Whitfield K 2007, 'The Health Education Impact Questionnaire (heiQ): an outcomes and evaluation measure for patient education and self-management interventions for people with chronic conditions', *Patient Education and Counseling*, vol. 66, no. 2, pp. 192–201.

Osborne R, Batterham R, Elsworth G, Hawkins M, Buchbinder R 2013, 'The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ)', BMC Public Health, vol. 13, no. 658, pp. 1–17.

Parry C, Kent E, Forsythe L, Alfano C, Rowland J 2013, 'Can't see the forest for the care plan: A call to revisit the context of care planning', *Journal of Clinical Oncology*, vol. 31, no. 21, pp. 2651–2653.

Queensland Health 2013, *Nurse-led clinics service delivery model*, Queensland Health, viewed 18 September 2014, <a href="http://www.health.qld.gov.au/caru/improving-services/sdm-nurse-led.asp">http://www.health.qld.gov.au/caru/improving-services/sdm-nurse-led.asp</a>>.

Richardson J, Atherton Day N, Peacock S, Lezzi A 2004, 'Measurement of quality of life for economic evaluation and the Assessment of Quality of Life (AQoL) Mark 2 Instrument', *Australian Economic Review*, vol. 37, no. 1, pp. 62–88.

Richardson J, Sinha K, Lezzi A, Khan M 2011, *Modelling the Utility of Health States with the Assessment of Quality of Life (AQoL) 8D instrument overview and utility scoring algorithm*, Centre for Health Economics, Monash University, Melbourne.

Salz T, Oeffinger K, McCabe M, Layne T, Bach P 2012, 'Survivorship care plans in research and practice', *A Cancer Journal for Clinicians*, vol. 62, no. 1, pp. 101–117.

Schneider HP, Heinemann LA, Rosemeier HP, Potthoff P, Behre HM 2000, 'The Menopause Rating Scale (MRS): reliability of scores of menopausal complaints' *Climacteric*, vol.3, no. 1, pp. 59–64.

Sostaric D, Polack M 2014, Exercise intervention, physiological function and survivorship following Lymphoma treatment, viewed 25 September 2014, <a href="http://www.msahc.com.au/files/ljgcsvodxb/">http://www.msahc.com.au/files/ljgcsvodxb/</a> Leukaemia-Foundation-Jump-Start-Program.pdf>.

Steine S, Finet A, Laerum E 2001, 'The patient experience questionnaire: development, validity and reliability', *Family Practice*, vol. 18, no. 4, pp. 410–418.

Stenberg U, Ruland C, Miaskowski C 2010, 'Review of the literature on the effects of caring for a patient with cancer', *Psycho-Oncology*, vol. 19, no. 10, pp. 1013–1025.

The Coach Program 1995, *The Coach Program: achieving your risk factor targets*, The Coach Program, viewed 18 September 2014 <a href="http://thecoachprogram.com">http://thecoachprogram.com</a>.

Thursfield V, Farrugia H, Karahalios E, Giles G 2012 *Cancer survival in Victoria 2012: estimates of survival for 2006–2010 and comparisons with earlier periods*, Cancer Council Victoria, Melbourne, viewed 25 September 2014, <a href="http://www.cancervic.org.au/downloads/cec/cancer-survival-victoria-2012.pdf">http://www.cancervic.org.au/downloads/cec/cancer-survival-victoria-2012.pdf</a>.

Thursfield V, Staines C, Giles G, Farrugia H 2013, *Cancer incidence in Victoria: statistics and trends 2012*, Cancer Council Victoria, Melbourne, viewed 25 September 2014, <a href="http://www.cancervic.org.au/downloads/cec/cancer-in-vic/ccv-statistics-trends-2012.pdf">http://www.cancervic.org.au/downloads/cec/cancer-in-vic/ccv-statistics-trends-2012.pdf</a>>.

Ware, JE, Kosinski M, Keller SK 1994, *SF-36 physical and mental health summary scales: a user's manual*, The Health Institute, New England Medical Center, Boston.

Watson E, Rose P, Neal R, Hulbert-Williams N, Donnelly P, Hubbard G, Elliott J, Campbell C, Weller D, Wilkinson C 2012, 'Personalised cancer follow-up: risk stratification, needs assessment or both?', *British Journal of Cancer*, vol. 106, no. 1, pp. 1–5.

