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health

Supporting cancer survivors in Victoria: summary report

Learning from the Victorian Cancer
Survivorship Program pilot projects
2011–2014

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Foreword

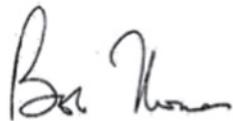
Preparing cancer survivors for life after cancer should be an integral part of providing care. With increasing numbers of survivors and improved understanding of the range of challenges experienced post-treatment, new approaches are required. Current models of care are ill-equipped to cater for these 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' to address 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 summarises the lessons we learned through the VCSP projects. The target audiences for this report are policymakers, health service managers, health professionals, cancer-related non-government organisations, primary care organisations and interested consumers.

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

Why survivorship programs? – a case study

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 per cent 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

Introduction

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; 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 Department of Health initiated the Victorian Cancer Survivorship Program (VCSP) in 2011 to pilot new models of survivorship care within the health system. The program aimed to: trial collaborative models of care across acute and primary/community care sectors; evaluate interventions for effectiveness, acceptability, sustainability and transferability; and facilitate survivor involvement and self-management. It sought to improve our understanding of the specific survivorship care needs of different groups, to develop resources tailored to survivors' and health professionals' needs and to 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 populations of survivors. Most projects recruited survivors within 12 months of their treatment for early-stage cancer ending.

- 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 GPs providing follow-up care for 'low-risk' survivors, 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.

For a summary of the six projects refer to Table 1.

Table 1: Summary of the Victorian Cancer Survivorship Program pilot projects

Project	Project partners	Intervention
Survivorship program for patients completing definitive breast cancer treatment	The Royal Melbourne Hospital, The Royal Women's Hospital, Western Hospital, BreaCan, Inner North West Melbourne Medicare Local	Survivors with early breast cancer were risk stratified to shared care follow-up with GPs at the multidisciplinary meeting. Participants were offered a face-to-face or telephone-delivered nurse-led clinic (NLC) consultation for: education; psychosocial, physical and treatment-related concerns; referrals; and development of SCPs. Nurses facilitated shared care arrangements with nominated GPs.
Barwon South West Survivorship Project: Improving outcomes for survivors of cancer	Barwon South Western Regional Integrated Cancer Service, Barwon Health, Western District Health Service, Barwon Medicare Local, Great South Coast Medicare Local, Deakin University	SCPs and one-page tumour-specific surveillance schedules for GPs were developed for eight tumour streams. Nurse-led services were created across three sites, offering two consultations to participants for SCP development, health education, supportive care screening, care coordination and assisted transition to shared care with nominated GPs.
Melanoma shared care: A tripartite approach for survival – the patient, their GP and their specialist	Victorian Melanoma Service (Alfred Health), Gippsland Regional Integrated Cancer Service, Southern Melbourne Integrated Cancer Service, Peninsula General Practice Network, Melanoma Patients Australia	Following acute treatment, an ongoing surveillance plan was developed by cancer specialists in consultation with survivors. Low-risk melanoma survivors were discharged to GP follow-up. Participants were given a diary resource summarising their treatment and the surveillance plan. Electronic reminders were generated at key time points to support survivors to better self-manage, self-assess supportive care needs and perform skin self-examinations. A brief discharge summary was provided to nominated GPs.
Survivorship Connections: A model of youth-friendly survivorship care	ONTrac at Peter Mac Victorian Adolescent and Young Adult (AYA) Cancer Service, The Royal Melbourne Hospital, Bendigo Health, CanTeen Australia, The University of Melbourne, Victorian and Tasmanian Youth Cancer Advisory Board	AYA specialists supported care coordinators across sites to deliver developmentally appropriate supportive care screening, assessments and interventions to AYA survivors. Care coordinator interventions occurred alongside routine cancer follow-up. Survivors were encouraged to engage with primary care. SCPs were developed with survivors and shared with nominated GPs.
Moving forward with confidence project: Increasing the capacity for self-management in cancer survivors	North Eastern Melbourne Integrated Cancer Service, Austin Health, Eastern Health, Northern Health, Cancer Council Victoria, Queensland University of Technology	Oncology nurses supported survivors to develop wellbeing-focused SCPs and in self-management. The Cancer Council Victoria nurse helpline service provided follow-up telephone support 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.
Positive change for life project: Improving health, wellbeing and quality of life for survivors of blood cancer following stem cell transplantation	Alfred Health, Southern Melbourne Integrated Cancer Service, The Leukaemia Foundation	This was a 12-month program of individualised community-based physical activity, nutrition support, group activities and motivational support. All participants received face-to-face and telephone dietetic support, a physical activity plan tailored to their needs/preferences and cost-neutral memberships to fitness centres. Participants were referred to exercise physiology if indicated.

Outcomes, lessons, challenges and enablers

Variability of project design posed challenges for evaluation and limited direct comparisons. Individual project evaluations were also affected by issues such as delays in obtaining ethics approval and low recruitment numbers. These issues impacted on the ability of projects to demonstrate robust outcomes within project timeframes. This report summarises common outcomes, 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 *Chronic disease management plans* (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 or to discharge for 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 reaccess to specialist care.

Health literacy

Two projects measured health literacy and health education impact. Both reported relatively high baseline function and some positive shifts in the domains of health literacy and health education impact. The Barwon South West Survivorship Project in particular reported significant improvements in the domains of; 'perceived health care provider support' ($p = 0.025$), 'critical appraisal' ($p = 0.001$) and 'navigating the health care system' ($p = 0.04$). In the setting of high health literacy, the challenge lies in choosing tools that are sensitive to measure positive change.

Models of care

a. Shared care with GPs or discharge for 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 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, although preferences for scheduling varied. 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. In a number of the projects, establishing stronger linkages between health services and the community-based organisations improved access to services and support 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 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 practice nurses, as well as those working for acute cancer 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 (The University of Melbourne) and General Practice Victoria completed an overarching workforce evaluation; its key recommendations for policy, practice and research will be included in the full project report, due for publication in early 2015.

Summary of learnings

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 process of identifying patients at the end of their treatment. They can also help generate SCPs and with 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 survivor readiness to engage with survivorship planning varies.
- It is important to prepare survivors during treatment for the potential impacts of cancer.
- Empowering survivors to seek post-treatment information and support is important.
- Preparing survivors early for GP follow-up helps them to accept shared care.

Recommendations

- Develop information technology systems solutions to identify survivors prior to the end of their treatment and to populate treatment summaries.
- Promote active discharge planning for transitioning care.
- 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 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'.
- Improve access to needs assessments and care coordination following treatment. Develop validated tools and consider conducting a 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 of 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
 - evaluate the economic and longer term impacts of these models on survivor outcomes.
- Risk-stratification approaches are required to better 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, re-design programs, change management approaches and 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 health services to more flexibly cater for the needs of increasing numbers of survivors. Considering the enablers and challenges identified in this summary report will help when implementing future survivorship initiatives.

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