



From the Director

The Australian Cancer Survivorship Centre, a Richard Pratt legacy (ACSC) is based at Peter MacCallum Cancer Centre (Peter Mac) in Parkville. We receive funding from the Victorian Department of Health and Human Services, The Pratt Foundation and Peter Mac.

The ACSC aims to improve outcomes for people affected by cancer. We work with clinical providers (medical, nursing, allied health) at Peter Mac, our clinical partners in Parkville and throughout Victoria, as well as survivors and a range of organisations to enable improved care for survivors, their families and carers. The ACSC has a statewide role in the development of education and resources for both survivors and health professionals. We provide advice regarding models of care. While our focus is not primarily on research, we strongly support and collaborate in research relevant to cancer survivorship.

For more information or to explore opportunities to collaborate, please email contactacsc@petermac.org or phone +61 3 8559 6220.

This *Year in Review* summarises highlights from 2018.

Professor Michael Jefford

YEAR IN REVIEW 2018



Photo: Participants enjoying the presentations at the 2nd Victorian Cancer Survivorship Conference.

Trialling novel models of care

Victorian Cancer Survivorship Program

The VCSP has been supporting initiatives for Victorian cancer survivors since 2011.

Following the success of the 2011–14 round of VCSP funding, the Victorian Government introduced a second phase of grants funding, for 2016–19. In 2016, 13 applications were successful and in 2017, a further six capacity building grants were supported.

In 2018, five more projects were funded. The 2018 projects target survivors with poorer outcomes, including people treated for brain tumours or advanced melanoma, the elderly, and survivors living in rural and regional areas. Further information is available at: www2.health.vic.gov.au/about/health-strategies/cancer-care/cancer-projects/victorian-cancer-survivorship-program

All 24 VCSP projects will be complete by the end of 2019. The ACSC is working with

the Victorian Government to undertake an evaluation of the second phase of the VCSP. The evaluation will inform future survivorship work in Victoria.

The ACSC provides support to the VCSP by developing resources for survivors and health professionals and by convening and facilitating a Community of Practice. The Community of Practice brings together staff working on VCSP-funded projects and many others committed to improved post-treatment care. Further information is available at: www.petermac.org/services/support-services/australian-cancer-survivorship-centre/health-professionals/victorian

The ACSC has been pleased to offer advice to a number of the VCSP projects, at Peter Mac and the Parkville precinct, and across the state.



Educating health professionals

We provide important education and training activities in survivorship care, based on early ACSC work that revealed a need for more education and training for health professionals about survivorship care. International reports also underscore the need for education of healthcare providers in survivorship care. Here we highlight some of our work in 2018.



Photo: Participants at the 2nd Victorian Cancer Survivorship Conference in February.

The 2nd Victorian Cancer Survivorship Conference

The 2nd Victorian Cancer Survivorship Conference was an outstanding success.

The ACSC played a major role in delivering the conference, which was hosted by the Victorian Comprehensive Cancer Centre and Peter Mac and held on 8–9 February at the Walter and Eliza Hall Institute of Medical Research, Melbourne. The conference showcased a variety of high-calibre national and international speakers, while also featuring personal survivor stories and a memorable debate.

Almost 300 delegates attended. Delegates came from across Australia and overseas; they were from a variety of health disciplines, government and non-government agencies, and research areas.

International speakers were:

- Dr Jonathan Sussman, a radiation oncologist and Director of the Supportive Care Research Unit at the Juravinski Cancer Centre, and Director of the Program in Transitions in Care within the Applied Health Research Network of the Ontario Ministry of Health and Long-Term Care
- Professor Lonke van de Poll-Franse, Professor of Cancer Epidemiology and

Survivorship at Tilburg University, Group Leader at the Netherlands Cancer Institute and Senior Researcher at the Comprehensive Cancer Organisation Netherlands.

Attendees also heard from two prominent national speakers:

- Professor Janette Vardy, a medical oncologist and clinician researcher at the Concord Cancer Centre, University of Sydney
- Professor Phyllis Butow, NHMRC Senior Principal Research Fellow, President of COSA and Founding Director of the Psycho-Oncology Cooperative Research Group, also from the University of Sydney.

As with the first conference, we were delighted by the number and quality of abstract submissions. We heard many excellent presentations from local and international submissions. Feedback from attendees has been overwhelmingly positive, and our plan is to hold a third meeting in early 2020.

More information is available at: www.survivorshipconference.com.au

Survivorship care plans

The survivorship care plan (SCP) database is a much-needed and exciting initiative of the ACSC, which we continued to develop in 2018.

SCPs generally comprise a summary of a person's cancer diagnosis and treatment, as well as plans for follow-up, and information and resources to remain well. SCPs support the transition from treatment to post-treatment.

SCPs have been widely endorsed. They were a key recommendation of the landmark 2006 Institute of Medicine report, *From Cancer Patient to Cancer Survivor: Lost in Transition*. In Australia, the Optimal Care Pathways recommend that survivors be provided with a treatment summary and follow-up care plan after completing initial treatment. The Clinical Oncology Society of Australia (COSA) Model of Survivorship Care also strongly supports SCPs. With funding from the Department of Health and Human Services, in 2017 we developed an SCP database. It is an evidence-informed, best-practice database of key components of SCPs for survivors of breast, prostate and colorectal cancer. The database has been widely distributed and well received.

With further funding from the Western and Central Melbourne Integrated Cancer Service, we are now developing a web interface to the database, which will assist in the easy development of SCPs. We expect to complete this part of the project in the first quarter of 2019.



GP forum

The ACSC played a major role in facilitating the annual GP Forum at Peter Mac, held on Saturday 27 October. We are delighted that 126 GPs and practice nurses attended and that feedback has been very positive.

The annual forum provides an update on the latest cancer therapies and follow-up in primary care, and is presented by specialists from Peter Mac in collaboration with Cancer Council Victoria.

The forum aims to provide relevant clinical education to GPs and primary care nurses about new and evolving cancer treatments, their side effects and the information primary care professionals need to manage follow-up. This year's forum covered survivorship topics including cancer-related fatigue, return to work issues, nutrition and exercise.

Presentations are available at:
www.armchairmedical.tv/petermac-gp-forum-2018

Photo: General practitioners and practice nurses at the GP forum held at Peter Mac in October.

Primary care placement program

This program continues to grow and thrive.

In recognition of the critical role of general practice (primary care) in all stages of cancer care, the ACSC conducted a clinical placement pilot project in 2015, which brought together general practice and cancer specialist teams at Peter Mac to encourage bidirectional learning, strengthen links and build partnerships of care. GPs and primary health care nurses attended multidisciplinary team meetings and multidisciplinary clinics.

In 2016, the Victorian Department of Health and Human Services provided further funds to expand the placement program. The ACSC developed a toolkit and videos to support the program and promote the role of primary care and shared care. The program was feasible across multiple sites and considered clinically and professionally valuable. GPs and nurses reported improved knowledge and confidence regarding survivorship care.

In 2017 we embarked on a further phase of the Clinical Placement Program in Cancer Survivorship. The program aims to improve survivors' access to quality cancer survivorship care by enhancing the confidence and capability of primary care practitioners (PCPs), including GPs, practice nurses and allied health practitioners. Participation in the program aims to:

- improve PCPs' knowledge and confidence regarding cancer survivorship care

- improve understanding of the discipline-specific roles required for shared care
- enhance links between PCPs and hospital-based professionals.

The program has offered placements since January 2018. Eight Victorian public hospitals with cancer services are providing placement opportunities across a broad range of clinics. We have seen strong interest from nurses and allied health professionals, and have already met targets for these groups. We continue to recruit GPs and hope to recruit a total of 100 professionals.

Further information is available at:
www.petermac.org/education/survivorship-education

Delivering Innovative Cancer Survivorship Care

We continue to run Delivering Innovative Cancer Survivorship Care workshops. These events provide an opportunity for healthcare professionals to learn about current evidence, clinical guidelines, resources, practical tools, and consider their own clinical context to develop their knowledge around cancer survivorship and increase their capacity to implement survivorship care. We have had great interest in the workshops and participants report them to be relevant and of practical benefit.

New information materials

The ACSC has produced a wide range of fact sheets and other resources for health professionals. In 2018, we added a new fact sheet, targeted primarily for GPs, 'Follow up of survivors of endometrial cancer.'

Other resources for health professionals are available at: www.petermac.org/services/support-services/australian-cancer-survivorship-centre/health-professionals/resources-and

Information and education for survivors

We develop and deliver resources to meet the information and support needs of survivors, often in collaboration with other organisations. Here we highlight examples from our 2018 work.



Left-Right: Amanda Piper (Previous ACSC Manager), Prof Michael Jefford (ACSC Director), Dorothy Yiu (President, Chinese Cancer & Chronic Illness Society of Victoria), Dr David Speakman (Chief Medical Officer, Peter Mac).



Information in other languages

Migrants with cancer report worse quality of life, higher levels of distress and greater levels of unmet needs, compared with English-speaking, Australian-born survivors. They also report a need for culturally appropriate information written in their own language.

Previously, with funding from Cancer Australia, the ACSC has worked with partners—including Peter Mac's Department of Cancer Experiences Research, the Psycho-oncology Co-operative Research Group and several Cancer Councils—to develop new information materials for people who speak Cantonese, Mandarin, Vietnamese, Arabic, Greek and Italian.

In 2018 we completed a third project, funded through Cancer Australia's Supporting People with Cancer initiative. In partnership with Cancer Councils and the Breast Cancer Network Australia, we produced new written resources for people who speak Hindi and Tagalog, audio resources in English, Cantonese and Mandarin, a low-literacy written resource and a cancer glossary, available in 15 languages. Additionally, we held face-to-face



Photo Top: Nicole Kinnane, Ashlee Bailey and Jenn Kent (ACSC) showcasing the release of the multilingual cancer glossary and the culturally and linguistically diverse cancer resources. **Photo Bottom:** Participants viewing the 'On the Road to Recovery – Life after cancer' video in Chinese.

seminars for Chinese-speaking cancer survivors and have developed new video resources in Chinese. We were pleased to launch these resources in June 2018.

These and a variety of other resources are available at: www.petermac.org/services/support-services/australian-cancer-survivorship-centre/survivors-and-carers/resources

The cancer glossary is at: www.petermac.org/multilingualglossary

We have also developed language-specific information pages, to collate resources available in particular languages. See: www.petermac.org/languages

New fact sheets for survivors

In 2018, we developed new fact sheets for survivors: 'How your general practice can support you to live well' and 'Survivorship care plans: What are they and how you can use them'. They complement a number of other resources, collected at: www.petermac.org/services/support-services/australian-cancer-survivorship-centre/survivors-and-carers/resources

Wellness and Life after Cancer

In collaboration with Cancer Council Victoria, the ACSC provides regular face-to-face sessions for survivors, their family members, carers and friends. Held at our main site in Parkville, the sessions provide an opportunity for people to share their own experiences, learn strategies to manage their own health and wellbeing, and link to a range of supports and services.

We held two very successful events in 2018, with over 50 people attending each event. In 2019 we aim to deliver a variety of events to support survivors, their families and friends.

Survivors' stories

We continue to build on our collection of survivors' stories. Included in each story are different survivorship experiences as well as details of services or supports that have assisted people in their treatment and recovery. Survivors report these stories to be interesting, helpful and inspirational.

The stories can be found at: www.petermac.org/services/support-services/australian-cancer-survivorship-centre/survivors-and-carers/resources

Collaborating with and learning from others

We learn from and collaborate with groups with shared objectives, including a number of consumer and professional organisations, cancer charities and government agencies. Below are some highlights from 2018.



Photo: Dr Karolina Lisy (ACSC & Department of Cancer Experiences Research) presenting at the NGO forum in June.

Forums with non-government organisations

In recognition of the critical role that non-government organisations (NGOs) play in supporting cancer patients and survivors, the ACSC convened two forums in 2018 with representatives from many NGOs, to learn from each other and build collaboration. There was clear acknowledgment of the opportunity to share experience and to work collaboratively with the goal of improving care and outcomes for survivors, carers, families and friends.

Initial work will develop a position statement on the role of NGOs in survivorship care. The ACSC will also collate and share existing survivorship work across the NGO sector.

Victorian Cancer Survivorship Research Forum

There is considerable momentum around cancer survivorship in Victoria, and indeed across Australia. In Victoria, a major emphasis has been on projects funded through the VCSP. However, there is also a significant amount of survivorship-focused research.

In an effort to bring together health professionals and other researchers working in cancer survivorship, in September, we held a first Victorian Cancer Survivorship Research Forum. The forum was arranged to build awareness of the breadth of survivorship research, facilitate collaboration, and consider how survivorship-focused research can be supported in Victoria.

We have had strong support for the forum, and will consider a number of opportunities to support collaborations and build capacity. We are also keen to work with the COSA survivorship group, to see whether this model can be expanded beyond Victoria.



Meeting presentations

In 2018, ACSC staff presented work at a number of national and international meetings:

- Victorian Cancer Survivorship Conference in Melbourne (February)
- The University of Texas MD Anderson Cancer Center Global Academic Programs Conference in Stockholm (May)
- Cancer Nurses Society of Australia Annual Congress in Brisbane (June)
- Multinational Association of Supportive Care in Cancer / International Society of Oral Oncology Annual Meeting in Vienna (June)
- European Cancer Rehabilitation and Survivorship Symposium in Copenhagen (September)
- International Gynecologic Cancer Society Biennial Meeting in Kyoto (September)
- World Cancer Congress in Kuala Lumpur (October)
- Australasian Melanoma Conference in Melbourne (October)
- World Congress of Psycho-Oncology in Hong Kong (October–November)
- Asia Pacific Neuroendocrine Tumour Society Annual Meeting in Melbourne (November)
- COSA Annual Scientific Meeting in Perth (November).

ACSC staff are pleased to work closely with local and international cancer survivorship organisations, including the COSA Survivorship Group and the Cancer Survivorship Committee of the American Society of Clinical Oncology.

Planning ahead

Some of our work in 2019 will include:

- completing a web interface, linking to our SCP database, to promote SCP delivery
- launching a new 'survivorship directory' on our website, to act as a central repository for common survivorship issues and concerns
- presenting our work at the Flinders/COSA Cancer Survivorship Conference in Sydney (March 2019)
- producing guidance to support shared care for cancer survivors (sharing care between cancer providers and GPs)
- working with the Wellness Centre at Peter Mac, and others, to deliver a range of supportive programs for cancer survivors
- completing the current phase of the Clinical Placement Program in Cancer Survivorship
- supporting the evaluation of the VCSP, and shaping Victorian efforts to improve outcomes for cancer survivors
- undertaking an evaluation of our suite of resources for cancer survivors
- supporting and growing the cancer survivorship research community in Victoria
- working with and hosting further forums with non-government organisations
- working with the VCSP, the COSA Survivorship Group, Cancer Australia and other agencies to support improved cancer survivorship care
- planning our 10-year celebration (the ACSC was founded in 2009 and our official launch event was in August 2010)
- expanding education and training opportunities for health professionals
- publishing results from completed projects in the peer-reviewed literature.

Published work from ACSC and related work from the Department of Cancer Experiences Research

- Lisy K, Peters MDJ, Schofield P & Jefford M, 2018, 'Experiences and unmet needs of lesbian, gay and bisexual people with cancer care: A systematic review and meta-synthesis', *Psychooncology*, 27(6):1480–9. [Epub 5 March]
- Lisy K, Denehy L, Chan RJ, Khan F, Piper A & Jefford M, 2018, 'The current state of cancer rehabilitation in Australia', *J Cancer Rehab*, 1:9–13.
- Lisy K, Ward A, Schofield P, Hulbert-Williams N, Bishop J & Jefford M, 2018, 'Patient-reported outcomes of sexual and gender minority cancer survivors in Australia', *Psychooncology*, 3 December. [Epub ahead of print]
- Findley PA, Jefford M, Johanssen C & Chang ASK, 'International perspectives', Chapter in *Handbook of Cancer Survivorship*, 2nd edition, edited by Feuerstein M & Nekhlyudov L, Springer.

Australian Cancer Survivorship Centre

A Richard Pratt Legacy



Australian Cancer Survivorship Centre

Locked Bag 1, A'Beckett Street
Melbourne VIC 8006

Email: contactacsc@petermac.org

www.petermac.org/cancersurvivorship



Peter Mac
Peter MacCallum Cancer Centre
Victoria Australia

