



YEAR IN REVIEW 2020



At the 3rd Victorian Cancer Survivorship Conference. From left: Prof Deb Mayer, Helana Kelly, Kyleigh Smith, Anton Enus, Prof Jon Emery, Prof Michael Jefford, Michelle Barrett.

Message from the Director



The Australian Cancer Survivorship Centre (ACSC) aims to improve outcomes for people affected by cancer. We work with clinical providers (medical, nursing and allied health) at Peter MacCallum Cancer Centre (Peter Mac) and throughout Victoria, as well as survivors and a range of organisations, to enable improved care for survivors, their families and carers.

We are very grateful for ongoing funding from Peter Mac and the Victorian Government to support our work.

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, and while our focus is not primarily on research, we strongly support and collaborate in research relevant to survivorship.

2020 was a challenging year for many. COVID-19 continues to affect many aspects of our lives, including the way we deliver and receive healthcare. We thank our colleagues across all sectors of healthcare and the community for your ongoing work to support cancer survivors and their families. We look forward to continuing to work with you in 2021.

We invite you to read our 'Year in review', which highlights our many achievements in 2020, including celebrating our 10th birthday and co-hosting the 3rd Victorian Cancer Survivorship Conference.

To learn more about the ACSC or to explore opportunities to collaborate, visit our website petermac.org/cancersurvivorship, email contactacsc@petermac.org or phone +61 3 8559 6220.

Professor Michael Jefford



10-year birthday

The ACSC celebrated 10 years of service in 2020! Since 2010, the ACSC has been providing information and support to survivors and carers, education and training for health professionals, and cancer survivorship leadership and guidance. We are immensely proud of our achievements to date, and grateful for your support and input into our work.

Some highlights from 2020			
 <p>PMA 2020 PETER MAC AWARDS WINNER OF World-Class Cancer Education</p>	 <p>3RD VICTORIAN CANCER SURVIVORSHIP CONFERENCE A 2020 VISION BUILDING ON LEARNING... PARTNERING FOR SUCCESS hosted almost 200 local and international delegates</p>	 <p>eviQ Education launched six free modules on cancer survivorship</p>	
 <p>Common Survivorship Issues Directory accessed over 6,500 times</p>		 <p>Victorian Cancer Survivorship Community of Practice hosted virtually with over 80 participants</p>	
 <p>Developed cancer survivorship resources for 6 new languages with WCMICS funding</p>			

ACHIEVEMENTS IN 2020

On the following pages, we summarise our 2020 achievements under six headings that reflect our refreshed strategic plan.

1. Provide information and support for cancer survivors and carers

Throughout 2020, we continued to develop and provide information and support for cancer survivors and carers.

A principal means of delivering information for survivors is the ACSC website petermac.org/cancersurvivorship, which attracted many readers in 2020. 'Breast cancer: follow-up of survivors of breast cancer' was the most frequently downloaded resource, with more than 170 downloads. We also added information to the website about 'Self-management', promoting the value of taking control of one's own health by acquiring information and skills that help survivors cope with cancer treatment and follow-up.

Common Survivorship Issues Directory

This directory petermac.org/survdirect is a central hub for commonly experienced cancer survivorship issues, offering information and tools to support cancer survivors. In 2020 the directory was expanded to include three new topics, bringing the total number of topics to 13. The directory was accessed 6526 times, with cancer-related fatigue being the most widely accessed issue.

Resources for culturally and linguistically diverse groups

The ACSC partnered with the Western and Central Melbourne Integrated Cancer Service (WCMICS) to develop new resources for culturally and linguistically diverse groups. This included translating the written resource 'How to prepare for check-ups' into six languages (traditional Chinese, simple Chinese, Greek, Italian, Arabic, Vietnamese) and developing an audio-recording 'On the road to recovery' in six languages (Arabic, Italian, Greek, Vietnamese, Tagalog, Hindi). A [promotional video](#) was also created to support health professionals to effectively deliver cancer survivorship information to people from culturally and linguistically diverse backgrounds.

We thank WCMICS for their funding and support of this important project. To access these resources, please visit petermac.org/languages

Resources for young people

The ACSC proudly launched the 'Adolescents and young adults' page, providing resources and information for young survivors. The information was endorsed by the Victorian and Tasmanian Youth Cancer Action Board.

Webinars

In November, we presented the Cancer Wellness Program (previously known as Wellness and Life after Cancer) – an initiative of Cancer Council Victoria. Typically provided as a full-day, face-to-face event, the 90-minute webinar was attended by 38 cancer survivors among a total of 51 attendees. Videos on key topics are available to [view here](#).

We also proudly contributed to several consumer-focused webinars, including those convened by the Australia and New Zealand Sarcoma Association and Melanoma Patients Australia.

 **Common Survivorship Issues Directory**
petermac.org/survdirect

2. Provide education and training for health professionals

The ACSC continued to provide learning opportunities and develop resources for health professionals throughout 2020.

Cancer Survivorship course – eviQ

We re-launched our revamped, free online education for health professionals: ‘Cancer survivorship’. Hosted on eviQ Education (a Cancer Institute NSW site), this six-module introductory course is relevant for all health professionals interested or working in cancer survivorship. The course includes the most up-to-date evidence, explores the health needs of cancer survivors, and presents tools, guidelines, frameworks and strategies to provide optimal cancer survivorship care. Each module can be completed individually.

Please visit eviQ Education today and provide your feedback so we can continue to improve this important resource.

Module 1
Survivorship fundamentals
Cancer Survivorship

Module 2
Models of survivorship care
Cancer Survivorship

Module 3
A multidisciplinary approach
Cancer Survivorship

Module 4
Survivorship care plans
Cancer Survivorship

Module 5
Self-management
Cancer Survivorship

Module 6
Wellbeing
Cancer Survivorship



Panelists at the allied health survivorship webinar. From top left: Helen Gilby, Dr Fiona Lynch, Dr Nicole Kiss, Prof Ray Chan, Andrew Murnane, Denise Beovich, Helana Kelly, Lauren Atkins.

Delivering Innovative Cancer Survivorship Care

In December, 54 people attended the ‘Delivering innovative cancer survivorship care’ webinar. This free, virtual course was open to health professionals and included key survivorship issues including the common experiences of cancer survivors, promotion of wellness and self-management, and motivational interviewing techniques. Typically run face to face, this modified event still received excellent feedback, such as: *‘Thank you so much for this wonderful session, it is very beneficial for our daily nursing practice! Much appreciated!’*

Webinars

In August, the ACSC partnered with Cancer Council Victoria and the Clinical Oncology Society of Australia (COSA) to present a free, allied health cancer survivorship webinar on ‘The important role allied health plays in the care of cancer patients post-treatment – an interactive case review’. Three hundred and twenty-two health professionals watched the webinar live, and close to 200 have subsequently watched the recording, which you can access [here](#).

We also partnered with the Royal Australian College of General Practitioners, Cancer Council Victoria, the Australian Primary Health Care Nurses

Association, the Victorian Comprehensive Cancer Centre (VCCC) and COSA to deliver a survivorship-focused webinar for primary care health professionals, with 117 people in attendance, a further 186 have watched the recording, which you can access [here](#).

We were also pleased to be panellists at two Melbourne Metropolitan Primary Health Network webinars on implementing Optimal Care Pathways and a panellist at the Murray Primary Health Network webinar exploring the same topic.



Peter Mac award

The ACSC received a 2020 Peter Mac Award in the category ‘World-class cancer education’. Throughout 2020, the ACSC team delivered over one dozen high-quality education initiatives, providing education to more than 1000 health professionals.

3. Support improved models of survivorship care

Electronic medical record and survivorship care

Peter Mac, Melbourne Health and the Royal Women's hospitals all moved to the Epic electronic medical record (EMR) system in August 2020. The ACSC worked closely with clinical services and the EMR team to develop templates to support development and delivery of survivorship care plans. This will support continuity of care for cancer survivors and primary care providers post-treatment.

Quality framework for cancer survivorship care in Victoria

Funded by the Victorian Government, we undertook an environmental scan and literature review to develop a Quality Cancer Survivorship Framework as part of the broader project titled 'How do we define and measure optimal care for cancer survivors?' These informed an online modified reactive Delphi study conducted over two rounds. Participants were Australian and international, and included consumers, multidisciplinary healthcare providers, researchers, policymakers, and quality and accreditation staff.

Statements describing quality criteria for the Round 1 (R1) survey were presented in three domains: policy, process and outcomes, participants were asked to rate the importance of each of 68 criteria on a five-point scale, and could make comments and suggest additions. Quantitative data were analysed according to pre-determined scoring thresholds and results used to develop the Round 2 (R2) survey. In R2, participants ranked their 10 most important items within each domain.

Following R1, six criteria were removed, six were added, and 18 criteria were revised based on free-text comments. Following R2, 30 quality criteria were retained (the framework). These included presence of a policy for the provision of survivorship care, having processes for the assessment of emotional, psychological and physical effects and provision of services to manage issues, a process for stratification to different models of care, and collecting data on patient-reported outcomes, including quality of life, and survival rates.

This work is outlined in the Victorian Cancer Plan 2020–24, and the ACSC will continue the work in 2021.

Improving models of care throughout Victoria

The Victorian Government-funded project, 'Embed and spread optimal cancer survivorship across Victoria', aims to increase commitment to and awareness of cancer survivorship care. In 2020, the ACSC commenced Project 1, which will involve virtual educational roadshows to 15 Victorian cancer services, following a survey of sites' current survivorship services. Project 2 (guided by the results of Project 1) will expand mycareplan.org.au (currently available for survivors of early-stage breast, bowel and prostate cancers) to three further tumour types. Stay tuned for more in 2021!

Online survivorship care plan generator

mycareplan.org.au is an online survivorship care plan generator that was launched in 2019. 2020 saw 1722 users, with 358 care plans created. Successful funding from the Victorian Government will allow for expansion of mycareplan.org.au as part of the 'Embed and spread' project in 2021.

Resources

There is an agreed need to enhance the model of post-treatment care for cancer survivors. To enable more people to learn about models of survivorship care, in 2020 we:

- published 'Models of survivorship care' on our website
- developed 'Recommendations for implementing and delivering shared survivorship care' in both full and summary formats
- created a [rapid learning video](#) (3 minutes) to explain different models of care
- developed three short videos (3 minutes) on nurse-led follow-up care. The videos will be available in early 2021.

myCarePlan.org.au

4. Conduct and support survivorship research



The 3rd Victorian Cancer Survivorship conference

The 3rd Victorian Cancer Survivorship Conference was held in Melbourne just before COVID-19 restrictions. Co-hosted by the ACSC and the VCCC, we welcomed almost 200 local and international delegates.

The conference theme was 'A 2020 Vision – building on learnings, partnering for success'. Keynote speakers included Anton Enus, SBS nightly news anchor and ambassador for Bowel Cancer Australia, who shared meaningful insights into his lived experience as a bowel cancer survivor. International guests Professor Deborah Mayer (US) presented on 'Defining and delivering quality survivorship care' and 'Promoting healthy behaviours in survivors'. Professor Adam Glaser (UK) presented virtually on 'Patient-reported outcomes in survivors, also considering partners and carers' and 'Progress beyond the UK National Cancer Survivorship Initiative'. Professor Afaf Girgis reported on 'Trajectories of functioning in survivors and partners/caregivers' and 'Routine implementation of PROs in clinical care'.

Winners of the conference awards included:

- Best student presentation – Dr Victoria Garwood
- Best oral presentation – Nathan Harrison
- Best poster presentation – Paula Howell

Victorian Cancer Survivorship Research Forum

Hosted by the ACSC, the 4th Victorian Cancer Survivorship Research Forum was open to anyone interested or involved in cancer survivorship research. Held via webinar in November, the forum featured Prof Ray Chan who spoke about building successful research partnerships through the Queensland Collaborative for Cancer Survivorship. PhD candidate Imogen Ramsey (University of South Australia) discussed her work developing a core patient-reported outcome set for survivorship. Dr Maria Ftanou spoke about the study 'Feasibility and acceptability of Fear-less: a stepped-care program to manage fear of cancer recurrence in people with metastatic melanoma'.

Conference presentations

We continued to contribute to research, presenting at several conferences.

The 3rd Victorian Cancer Survivorship Conference

Convened in March 2020, presentations included Prof Jefford on 'Evaluation of the second phase of the Victorian Cancer Survivorship Program', 'SCORE: a randomised controlled trial examining shared care (oncology/general practice) for colorectal survivors' and (with Helana Kelly, Manager ACSC) 'Review and evaluation of the Australian Cancer Survivorship Centre'. There were further presentations from ACSC staff, including Dr Karolina Lisy and Nicole Kinnane.

ASCO Quality Care Symposium

The ACSC was pleased to present on 'Defining and measuring quality cancer survivorship care: an environmental scan'; the presentation can be accessed [here](#).

COSA Annual Scientific Meeting

COSA's 47th Annual Scientific Meeting focused on three themes: quality and safety, implementation science and cardio-oncology. The meeting was virtual for the first time and attracted a multidisciplinary group. ACSC's Karolina Lisy presented on the project 'How do we define and measure optimal care for cancer survivors?'

Global Academic Programs (GAP) conference

The theme for the GAP 2020 conference was 'New frontiers: leading inspired cancer care'. Co-hosted by Peter Mac the conference was fully virtual and connected members from across MD Anderson's 52 sister institution network. The conference explored how the integration of new technologies is changing cancer care, while also highlighting the importance of keeping patients central in thinking and practice. Prof Jefford and consumer advocate Meg Rynderman contributed to a webinar on survivorship care and Helana Kelly presented on the evaluation of the ACSC.



Student research

The ACSC continued to work with and support students during 2020. Lena Ly, a biomedicine honours student, completed work on the statewide quality framework for survivorship care in Victoria. Olivia Haeusler, an applied science (professional) student, commenced work on a pilot project relating to volunteers and cancer survivors at the Parkville precinct, which will be completed by the ACSC in 2021.

University Cancer Case Competition

The ACSC and the VCCC collaborated with the Australian Cancer and Health Sciences Competition to support the University Cancer Case Competition which, in 2020, encouraged undergraduate students to consider solutions to cancer survivorship issues. The competition received 72 registered teams (total 260 students), where 66 teams put forward submissions (compared to 44 received in 2019). The winning group, 'Climbing out of cancer', are undertaking a summer internship with the VCCC and the ACSC and will present to the Cancer Survivorship Advisory Committee in early 2021. The runner-up group, 'Transfer of trust, survivorship care program', presented to the committee in November 2020.

2020 publications

The ACSC continued to contribute to research publications.

Publications

The following 2020 publications were ACSC-led or in partnership with others at Peter Mac:

Garwood V, Lisy K, Jefford M. Survivorship in colorectal cancer: a cohort study of the patterns and documented content of follow-up visits. *J Clin Med* 2020 Aug 24;9(9):E2725. doi: 10.3390/jcm9092725.

Jefford M, Koczwara B, Emery J, Thornton-Benko E, Vardy J. The important role of general practice in the care of cancer survivors. *Aust J Gen Pract* 2020;49(5):288–92.

Lisy K, Kent J, Dumbrell J, Kelly H, Piper A, Jefford M. Sharing cancer survivorship care between oncology and primary care providers: a qualitative study of health care professionals' experiences. *J Clin Med* 2020 Sep 16;9(9):E2991. doi: 10.3390/jcm9092991.

Lisy K, Kent J, Piper A, Jefford M. Facilitators and barriers to shared primary and specialist cancer care: a systematic review. *Support Care Cancer* 2020 Aug 17. doi: 10.1007/s00520-020-05624-5.

Lisy K, Lai-Kwon J, Ward A, Sandhu S, Kasparian NA, Winstanley J, Boyle F, Gyorki D, Lacey K, Bishop J, Jefford M. Patient-reported outcomes in melanoma survivors at 1, 3 and 5 years post-diagnosis: a population-based cross-sectional study. *Qual Life Res* 2020 Mar 5. Online ahead of print.

Lynch FA, Katona L, Jefford M, Smith AB, Sham J, Dhillon HM, Ellen S, Phipps-Nelson J, Lai-Kwon J, Milne D, Russell L, Dax V, Diggins J, Kent H, Button-Sloan A, Elliott J, Shackleton M, Burrirdge H, Ftanou M. Feasibility and acceptability of fear-less: a stepped-care program to manage fear of cancer recurrence in people with metastatic melanoma. *J Clin Med* 2020 Sep 14;9(9):E2969. doi: 10.3390/jcm9092969.

Skandarajah AR, Lisy K, Ward A, Bishop J, Lacey K, Mann B, Jefford M. Patient-reported outcomes in survivors of breast cancer one, three and five years post-diagnosis: a cancer-registry based feasibility study. *Qual Life Res* 2020 Sep 30. doi: 10.1007/s11136-020-02652-w.

Other survivorship papers we were pleased to contribute to include:

Eakin EG, Reeves MM, Goode AD, Winkler EAH, Vardy JL, Boyle F, Haas MR, Hiller JE, Mishra GD, Jefford M, Koczwara B, Saunders CM, Chapman K, Hing L, Boltong AG, Lane K, Baldwin P, Millar L, McKiernan S, Demark-Wahnefried W, Courneya KS, Job J, Reid N, Robson E, Moretto N, Gordon L, Hayes SC. Translating research into practice: outcomes from the Healthy Living after Cancer Partnership Project. *BMC Cancer* 2020;20(1):963. doi: 10.1186/s12885-020-07454-4.

Howell D, Mayer DK, Fielding R, Eicher M, Verdonck-de Leeuw IM, Johansen C, Soto-Perez-de-Celis E, Foster C, Chan R, Alfano CM, Hudson SV, Jefford M, Lam WWT, Loerzel V, Pravettoni G, Rammant E, Schapira L, Stein KD, Koczwara B; Global Partners for Self-Management in Cancer. Management of cancer and health after the clinic visit: a call to action for self-management in cancer care. *J Natl Cancer Inst* 2020 Jun 11. Online ahead of print.

Mollica MA, Mayer DK, Oeffinger KC, Kim Y, Buckenmaier SS, Sivaram S, Muha C, Taib NA, Andritsch E, Asuzu CC, Bochs OV, Diaz S, Trill MD, Garcia PJ, Grassi L, Uchitomi Y, Shaikh AJ, Jefford M, Lee HJ, Johansen C, Luyirika E, Maher EJ, Mallillin MMB, Maniragaba T, Mehnert-Theuerkauf A, Pramesh CS, Siesling S, Spira O, Sussman J, Tang L, Hai NV, Yalcin S, Jacobsen PB. Follow-up care for breast and colorectal cancer across the globe: survey findings from 27 countries. *JCO Global Oncol* 6:1394–1411.

Book chapter

Lisy K, Hulbert-Williams N, Ussher JM, Alpert A, Kamen C & Jefford M. Lesbian, gay, bisexual, and transgender issues. In: M Watson & D Kissane (eds), *Sexual health, fertility, and relationships in cancer care*, Oxford University Press, 2020:1–10.

For more information on survivorship research, including current and completed projects, opportunities for students and publications, visit the [Survivorship and Living Well after Cancer page](#).

5. Provide leadership around cancer survivorship

Victorian Survivorship Community of Practice

The Victorian Survivorship Community of Practice brings together health professionals with an interest in cancer survivorship and the implementation of new models of care, providing an opportunity to discuss key aspects of cancer survivorship. With the July event cancelled due to COVID-19 restrictions, the October webinar agenda was full and attracted 80 attendees. Presenters included Ms Karen Botting (Department of Health and Human Services), Prof Janette Vardy (Sydney Cancer Survivorship Centre) and Prof Bogda Koczwara (Flinders Health and Medical Research Institute).

The Online Collaborative Workspace, which is open to interested health professionals, in 2020 consisted of 458 members. This online space is a forum to share ideas, events, project updates and more relating to cancer survivorship.

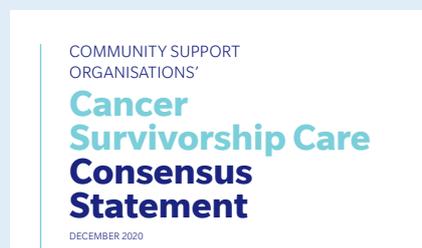
For further information or to join the Community of Practice or the Online Collaborative Workspace, email contactacsc@petermac.org.

Non-government organisation collaboration

Non-government organisations (NGOs) have an important role in supporting cancer survivors. The ACSC remains committed to working with NGOs to achieve optimal care and outcomes for cancer survivors. The 'Cancer survivorship in the NGO sector' forum was held in March, with 16 NGOs in attendance. The forum included presentations on the top six advocacy issues pertaining to cancer survivorship for NGOs, created opportunities for collaboration and facilitated discussion of the published consensus statement.

In July, the NGO Survivorship Advocacy Alliance Working Party prepared a letter to the Federal Minister for Health, strongly supporting the retention of telehealth item numbers through and beyond the COVID-19 period. A positive response was received from the Hon Greg Hunt MP acknowledging the position of the Alliance.

The [Community Support Organisations' Cancer Survivorship Care Consensus Statement](#) was updated in December 2020 with the inclusion of 12 additional signatories, bringing the total number to 31. The ACSC looks forward to continuing these partnerships in 2021. If your community support organisation would like to know more about NGO forums and the Alliance, please email contactacsc@petermac.org.



Committee membership

The ACSC continues to provide leadership in cancer survivorship on state, national and international committees. Examples of some (but not all) of the advisory committee work we do are below:

Prof Michael Jefford is Chair-Elect 2020–21 (to be Chair 2021–22) of the American Society of Clinical Oncology (ASCO) Cancer Survivorship Committee. This appointment – the first person from outside the United States to chair the committee – recognises Professor Jefford's international standing in cancer survivorship and his significant

contributions to service delivery, international literature, policy and program development. He is also the Chair of COSA's Cancer Survivorship Group and the Chair of the Survivorship Special Interest Group with the International Psycho-Oncology Society. Dr Karolina Lisy is an executive member of COSA's Cancer Survivorship Group.

Partnering with cancer survivors

The ACSC website includes a number of survivorship stories from consumers coordinated by ACSC consumer advocate, Meg Rynderman. Meg wrote her own survivor story 10 years ago and in 2020 published '[10 years on – my story retold](#)'. Videos of Meg and her husband, John, talking about their experience of cancer survivorship in brief videos, are available [here](#).

Meg also told Malcolm Chandler's story '[We didn't have slip slop slap back then](#)'.

We encourage you to read these [survivorship stories and more](#) by visiting the ACSC website.

6. Deliver a robust, collaborative and sustainable program



The team in 2020

We thank everyone who has worked with us this year!

Our website

During 2020, the [ACSC website](#) was accessed 26,047 times with 20,390 unique page views! People visiting our website spent an average of 1.28 minutes on the homepage. The most frequently viewed pages were the [ACSC homepage](#) and the 'Survivors and carers' page.

The ACSC is proud to provide resources for survivors, carers and health professionals. There were over 4000 downloaded PDF resources throughout 2020!

In 2020 we developed four newsletters and a Year in Review summary to add to our publications.

Social media

In February 2020, the ACSC launched our social media presence:



Twitter ([@ACSC_PeterMac](#)):

The ACSC had more than 200,000 Twitter impressions (number of times users saw ACSC's tweets). Since the inception of our Twitter handle in March, we have more than 380 followers and 240 tweets.



LinkedIn ([Australian Cancer Survivorship Centre](#)):

Follow the ACSC on social media for event updates, new resources and research!

Planning ahead

In 2021 and beyond, our plans include:

- launching the ACSC Strategic Plan 2020–25
- delivering the project 'Embed and spread optimal cancer survivorship across Victoria'
- continuing to develop and publish survivorship resources for consumers and health professionals on the ACSC website
- continuing to work with the Parkville electronic medical record team to incorporate survivorship resources
- presenting at the Flinders–COSA meeting Cancer Survivorship Conference [Life after Cancer - Redefined, Reimagined and Rebuilt](#), 18–19 March 2021, Adelaide
- working with Peter Mac and Parkville colleagues to improve the models of post-treatment care
- presenting and publishing our work
- planning for the 4th Victorian Cancer Survivorship Conference to be held in 2022
- delivering a volunteer-led survivorship pilot project with Parkville Head and Neck Cancer Services and Cancer Council Victoria.



Australian Cancer Survivorship Centre

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