

Cav Newsletter April-May 2019

About Cancer Action Victoria

CAV works with all those people who are diagnosed with cancer, as well as with their family, friends, and the Health Professions involved with their cancer from diagnosis to treatment to the new lease of life after the 'All Clear' is given. Whilst CAV acts as a resource for all cancer sufferers, CAV's focus is to actively assist and improve all patient care, particularly the post-cancer life treatment - through membership to CAV.

We are a member-based organisation, registered as a charity with the Australian Charities and Not-for-profit Commission.

CAV News

The Optimal Care Pathways Consumer Engagement Summit was held at Cancer Council Victoria on Monday the 8th of April and was attended by several CAV Committee members, either representing CAV, or representing other groups.

The objective of the national summit was to understand the needs and capacity of consumer organisations to promote and disseminate the consumer facing Optimal Care Pathways (OCPs), called the [What to Expect](#) guides.

The summit was facilitated by Dr. Norman Swan, and stimulated lively discussion among the attendees, from a diverse group of Cancer advocacy and support bodies.

Coming Events

The VICS (Victorian Integrated Cancer Conference) <https://vics2019.org> will take place 9-10 May 2019. CAV is sponsoring morning tea on the first day, and we are very pleased that the organising committee, led by Chair Joanne Gell, (pictured) has made 3 free registrations available for CAV Consumer members.



Cancer Consumer Training

CAV will shortly recommence Cancer Consumer Training in metropolitan locations, drawing upon the very successful regional training programme we developed last year with the support of the Victorian Government DHHS. Attendance costs are being kept to a minimum, thanks to the Government support in the courseware development. If you wish to receive such training please contact the CAV secretary at admin@canceractionvic.org.au to register your interest.

Knowing your rights as a Health Consumer

You could be forgiven, when you first enter into the receipt of medical services, for assuming that you have no rights in respect to your treatment and records. This is incorrect, especially in Victoria, where legislative support is already in place in respect to your RIGHT TO KNOW. Some of the relevant information is found in the Health Records Act.

<https://www2.health.vic.gov.au/about/legislation/health-records-act>

The *Health Records Act 2001* created a framework to protect the privacy of individuals' health information. It regulates

the collection and handling of health information.

<https://hcc.vic.gov.au/public/health-records>

Health service providers such as hospitals and dentists, and organisations such as schools, gyms, insurers, employers and government agencies, all collect and hold personal and health information as health records.

Privacy and Data Protection

<https://www.bettercare.vic.gov.au/privacy>

The *Privacy and Data Protection Act 2014* and the *Health Records Act 2001* regulate the information handling of personal and health information. It includes standards for information collection, storage, access, transmission, disclosure, use and disposal.

Request for access to Health Records

<http://www.each.com.au/wp-content/uploads/2017/06/request-for-records-1.pdf>

Cancer Council Victoria - Medical records and other privacy issues

<https://www.cancervic.org.au/cancer-information/treatments/making-decisions-about-your-care/medical-records-and-other-privacy-issues.html>

Health professionals will collect a lot of information about your health and the treatment you receive. A medical record contains personal information, so you need to know who can see it, change it and copy it.

<https://www.betterhealth.vic.gov.au/health/servicesandsupport/informed-consent-for-medical-treatment>

Informed consent means that you understand your condition and any proposed medical treatment. You have a legal right to be told any information that relates to your medical condition and treatment.

Research Projects that CAV supports

E-Health literacy.

Cancer Nursing Research Group at the University of Melbourne, led by Professor **Mei**

Krishnasamy, (pictured)

are working towards a study, setting out to develop a new instrument to assess e-health literacy among cancer consumers, in recognition of the growing number of apps, websites, and internet resources being developed for and recommended to cancer consumers. E-health resources are largely targeted at provision of information and promotion of self-care, but there has been little robust research to assess what consumers feel about e-health resources, how useful or trustworthy people feel they are, whether people know how to use them, or have the ability to tailor the information provided through these resources to their own needs. As a result, clinicians have no way of assessing who may or may not benefit from an e-health resource, and importantly when it may be safe to recommend an e-health resource to replace or compliment direct clinician contact. There will be three focus groups with a range of cancer consumers (patients or carers) to help explore peoples' views of e-health resources. We will then use that information to develop (what we think will be a world first) cancer e-health literacy measure that consumers and clinicians can use together to assess whether recommendation of an e-health resource is appropriate and safe for a patient and family members/carers.

CAV is represented in the research project team by our President, Marilyn Dolling.



The SIPI revolution, Standardised Individualised Patient Information for Cancer patients

Standardised Individualised Patient Information (SIPI) worksheets have been developed by the Victorian DHHS and associated Integrated Cancer Services for several cancer tumour-streams and are being developed for others.

The SIPI approach and format has now been adopted State-wide and is being considered by other States.

SIPI, in their simplest format, are two-page summaries, individualised for each patient, outlining the likely diagnostic and treatment process. They would be equally applicable to many non-cancer diagnoses.

SIPI are, however, “living documents” that change during the patient journey, and CAV consider that they would be most effective if also held in digital form, accessible, by consent, by cancer service providers.

CAV VP, Ian Dennis has been a member of the SIPI project Steering Committee

E-Health attitudes

Cav has also endorsed a new project, led by research body CIER Inc <https://cier.org.au/> which, in cooperation with CAV, and with the support of the CNRG at University Melbourne, wish to conduct a review and produce an index of attitudes to digital capacity and facilities relevant to e-health in general, (and SIPI in particular), to inform and assist in its application for the benefit of cancer patients and their carers, and to identify what people think are infrastructural and attitudinal impediments to effective implementation.

The index will draw upon the research methodology successfully applied by CIER Inc into the creation of the Australian Digital Cities Index, (ADCI is supported by AuDa (Australian Domain Name Authority) and Melbourne University.)

What would you like more information about?

If you would like a topic explored in our newsletter, just drop us an email at info@canceractionvic.org.au . We would love to hear from you.