

Cancer Voices Australia NEWS UPDATE

May 2016

Consumers Included “seal of approval” launched!



Cancer Voices is proud to announce that the Consumers Included concept is a reality. Its aim is to encourage and acknowledge those conference and event hosts who do support consumer involvement. Consumers may be assisted to attend relevant events with registration &/or travel expenses and be actively involved in event presentations. Already we have received seven EOIs, and one Application for logo use from a major cancer centre which meets the simple ‘Consumers Included’ criteria. For the information you need contact info@consumersincluded.org.au.

Thanks to all those who have encouraged us in this initiative – we look forward to seeing the Consumers Included distinctive logo on most cancer related events’ material.

Election Issues for Australians affected by cancer: Cancer Voices has contacted the major political parties, seeking their response to the five top priorities which resulted from the Australian Cancer Consumer Network (ACCN) Survey of late 2015. Political parties’ responses will be published on our website. ACCN priorities are:

- *Getting better and quicker access to cancer treatments: Timing of approvals for new cancer drugs and their subsidies is slow and lacks transparency. The consumer voice is not sufficiently heard in processes.*
- *Greater access to clinical trials with more trials available and more funding for trials here in Australia.*
- *Cancer Nurse/ Care coordinators/Patient Navigators: Cancer centres need to be able to fund the appropriate number and cancer-type positions to underpin this role.*
- *Access to drugs for less common cancers and improvements to access to off-label drugs for less common and rare cancers, where clinical trials may never happen, yet there is evidence of benefit.*
- *More information about treatment outcomes: Treatment outcomes vary greatly across different centres. We need a national cancer data registry so that treatment and outcomes can be tracked and reviewed across treatment centres, information which should be publicly available for informed choices.*

Australian Cancer Statistics; Strategy for Big Data: Consumers are keen for Australian cancer statistics to be collected and published in a timely and comprehensive fashion to inform decisions around effectiveness of treatments, variations in outcomes; also for planning health services and workforce based on emerging trends. This needs a collaborative ‘big picture’ MoonShot viewpoint about what cancer data is needed for meaningful interpretation eg by tumour type, stage at diagnosis, geographical and socioeconomic location, treatment etc. On the practical side we will investigate how agreement can be reached and implemented across the states.

Patient-reported outcomes in cancer studies: Cancer Voices supports the European Medicines Agency’s new guidance on the use of patient-reported outcome measures (PROMs) in cancer studies. It is an appendix to guidelines for the assessment of anticancer medicines.

http://www.ema.europa.eu/docs/en_GB/document_library/Other/2016/04/WC500205159.pdf

It’s important that Australia recognises the value of PROs in research and in clinical care, and for funding bodies to recognise this substantial gap in evidence, research, policy and practice.

Safety & Quality in Cancer Care: Concern caused by recent chemotherapy dosing “incidents” in South Australia and NSW leads us to consider calling more urgently for development of Best Practice Clinical standards of Cancer Care. While these have been available for radiation oncology (RANZCR 2011), and are largely followed informally, only Queensland has mandated them. Consumers would feel more secure if some kind of standards were in place for medical oncology. SA has also experienced serious issues in pathology results reporting. We also support the move to develop biobank guidelines.

Consumer Involvement in Research (CIR) - matching informed consumers to researchers’ requests:

Cancer Voices CIR Evaluation study has surveyed 70 requesting researchers and 80 CIR trained consumers about their learnings, experiences and recommendations arising from their engagement as working partners on cancer research projects. The project will report on institutions requesting consumer input as an essential grant criterion and those which have yet to do so. Results will be reported to the Sydney Cancer Conference and COSA later in the year.

Vale Bridget Whelan: We are deeply saddened by the news of the death of Bridget Whelan on 11 May. A great consumer advocate and contributor and well as friend to Cancer Voices at both state and national levels.