

Cancer Voices Australia NEWS UPDATE

March 2016

Australian Cancer Statistics in trouble: The AIHW reports that accurate cancer data for 2011 & 2012 is not possible due to the inability of NSW/ACT to provide their stats for incidence and mortality in time, meaning that 2012 national data must be estimates. There are specific adverse impacts for NSW itself. Cancer Voices is calling for the Cancer Institute NSW to allocate more of its budget so it can keep up with other states. This call is strongly supported by cancer researchers, clinicians and service planners. Data about progression to metastatic cancer remains high on our wish list, and on those of many other stakeholders.

MSAC approval for PET & SIRT: Cancer Voices has drafted new Position Statements on (i) Access to PET Scans and (ii) Access to Selective Internal Radiation Treatment (SIRT) for comment. Both issues, gaining MSAC approval and Medicare rebates for cancers other than those few currently approved, need to be acted upon in the interests of equity of access for those cancers which benefit from PET and SIRT. The finalised Position Statements will appear on our website in early April and form the basis of our advocacy thrust.

Priority issues for Australians affected by cancer: Stakeholders and Parliamentarians Supporting Cancer Causes have been advised of the top five issues identified by the recent survey of the 30-strong Australian Cancer Consumer Network, a number of whom requested the full report. The priority issues will also be used for advocacy efforts in the lead up to this year's federal election.

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

A busy time for the Cancer Voices CIR Program. So far in 2016, we have filled 36 requests for trained consumers from cancer researchers. We have 53 consumers active on one or more grant applications and/or funded studies, with a total of 83 on Cancer Voices' database. We are developing an electronic survey of researcher experience and satisfaction, as well as that of the matched consumers. Results will be reported to the Sydney Cancer Conference and COSA later in the year. The project will report on institutions requesting consumer input as an essential grant criterion, those which have yet to do so, and the range of research topics for which consumer input has been sought.

Implementing Radiation Oncology Practice Standards: Cancer Voices was invited to speak to the Tripartite Working Group which is looking at accreditation options for Australia's 74 radiation oncology centres. We applaud this move which would give cancer patients, and their referring doctors, full confidence about their standard of treatment.

Travel insurance for cancer patients: Following discussions with the Insurance Council of Australia (ICA), CVA expects the first useful product for traveling cancer consumers to be available in early April – a matrix showing which insurance companies offer what products, and how cancer risk is assessed by each. Cancer Voices has provided the industry body with an update on the current status of cancer treatment, and how this affects the length and quality of life.

Consumers attending cancer conferences: Cancer Voices welcomes the RANZCR's very positive response to our proposal that consumers should attend its Annual Scientific Meetings. We remain hopeful that Medical Oncology Group of Australia will do likewise. We are developing the criteria and logo for the "Consumers Included" seal of approval, which conference and event organisers will receive if those criteria are met, showing their commitment to real consumer engagement.

Cancer Voices NSW's Award for Excellence in Cancer Consumer Advocacy 2016: This year's Award, the fifth, was presented to Rosanna Martinello for her contribution over many years to improving the experience of young women with breast cancer, then achieving a number of wins for cancer consumers in general. Rosanna sits on several high level Boards and Committees, ably representing the views and needs of Australians affected by cancer. Her contribution was warmly acknowledged at the Cancer Council NSW's major Research Awards Event on 30 March.

Better HTA access to new cancer drugs & technologies: We attended another forum on this pressing topic, hosted by the University of South Australia and CaPPRE on 26 Feb. We are hopeful that this session's outcome will progress the message to the PBAC and to MSAC that some reform in the interests of consumer access & input is urgently needed.