

NSW Cancer Plan 2016-2020

Public Consultation Draft (21 September 2015): Cancer Voices NSW

Cancer Voices NSW, providing the independent and informed consumer view, has worked closely with the Cancer Institute NSW (CINSW) since CINSW's inception in 2003.

Cancer Voices NSW provides the independent voice of people affected by cancer in NSW, to improve the cancer experience of the over 40,000 people who are diagnosed each year. Established in 2000, we are active in the areas of diagnosis, information, treatment, research, support and care. To achieve this we work in partnership with decision makers and providers of these services, ensuring the patient perspective is heard from planning to delivery.

Cancer Voices has also worked closely with the CINSW on the development of the previous Cancer Plans, which have each reflected our role in cancer control in NSW. The 2011-2015 Plan refers to Cancer Voices NSW as a "collaborator" in achieving various goals in several places.

Under our role as a key stakeholder, Cancer Voices is particularly interested in the Cancer Institute's

Goal 2: to improve the survival of people with cancer, and

Goal 3: to improve the quality of life of people with cancer

We welcome NSW Health's three strategies which support these goals

- Keeping people healthy
- Providing world class clinical care
- Delivering truly integrated care

Our comments also reflect our support the Five Pillars of Cancer Control, the focus for consultation on the 2011-2015 NSW Cancer Plan

- (Preventing cancer)
- Detecting cancer early
- Improved services and professional development
- Cancer research
- Relevant cancer data and information

We thank the CINSW offering us the opportunity to comment on the present draft Plan.

We acknowledge our invited attendance and contribution at one of the consultation workshops earlier at this year.

Cancer Voices offers the following comments and recommendations, based on the considered contributions of its Executive Committee members:

- *There is no mention of consumers or community as major stakeholders*, or planned engagement with them over the life of the draft Plan. This should be rectified, especially in view of the CINSW legislated objectives, ACSQHC standards (especially Std 2) and the requirements on Local Health Districts to engage.
- *The general tenor is "medical model"*, i.e. top-down, and consequently mainly reflects the views of CINSW, rather than the experienced needs of our state's cancer consumers and community.
- *The list of "agencies"* (p 19) with which CINSW will work during the period of the plan mentions only two cancer charities and no cancer consumer organisations – an oversight?

- *Omission of many cancers*: A NSW Cancer Plan needs to contain concise information about the present NSW cancer scenario as its starting point. As a generic cancer consumer group, Cancer Voices is concerned that some cancers are not mentioned, despite their poor outcomes, especially the rare and less common cancers; also childhood and gynaecological cancers, other than cervical, are omitted. We suggest that a full page *table showing the full list of cancers*, male and female, including rare and less common, showing incidence and mortality be included in the Plan to guide its readers and indeed, service planners.
- *Early detection*: The Plan lists surveillance programs for breast, bowel and cervical cancers but makes no provision for prostate cancers for which NSW could initiate and become a state leader for this common and worrying cancer (p. 9, 12, 20).
- *Palliative Care*:
 - (a) The comment to “implement the NSW Government Plan to increase access to palliative care 2012- 2016” suggests this has not happened and has only a few months to achieve its goals. We note that this report is due for update next year and as such will be too outdated for the needs of the NSW Cancer Plan.
 - (b) Palliative care must to be recognised as part of the multidisciplinary team
 - (c) Cross referral to palliative care needs to be a fluid and integral part of cancer care
- *Major Data Issues* to address:
 - (a) **Updating NSW cancer stats**: Cancer Voices recommends that a major goal for the Plan should be to bring NSW cancer data up to date. Latest statistics are for 2010, which we believe is not appropriate for a Plan covering 2016-2020, as the statistics quoted for planning purposes are already six years behind the Plan’s starting year.
 - (b) **Clinical cancer data**: We also suggest that the Plan adopt the measure of a reasonable date by which to achieve collection of clinical cancer data. This is essential to provide the missing information in our cancer statistics – numbers of recurrences and metastases, by cancer type. Accurate planning of cancer services to reflect demand relies on this kind of data.
 - (c) There is no referencing data for the three “key focus cancers” which gives little justification for their selection.
 - (d) Graphs are provided or incidence but not mortality, which gives an incomplete picture of trends and needs in NSW (p 3-4)
 - (e) We suggest linkage to all data base resources for planning. This includes but is not exclusive to PBS, MBS data recording. Here CI NSW data can support and validate other data collections (p. 21)
 - (f) Access to data held by CINSW is currently difficult, as reported by NSW cancer researchers: the Plan should emphasize that bureaucratic processes will be improved in this area. (p16)
- *Survivorship*: reference to this extremely important aspect is lightweight and needs to be upgraded. The definition accepted by COSA, and Cancer Voices, is that a survivor is: *An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. See the National Coalition for Cancer Survivorship*
<http://cancercontrol.cancer.gov/ocs/statistics/definitions.html>.

The plan does not mention the importance of cancer care coordination, treatment and care plans, follow-up regimes or surveillance – all key aspects of survivorship.

- *Cancer Workforce Planning*: Another essential element for the Cancer Plan which appears to have been omitted. Supply and demand of cancer health professionals, including cancer nurse coordinators, oncology social workers and allied health professionals, is a major facet of a good cancer service and we recommend should be included in the NSW Plan, and as an

outcome measurement. Due to the overall aging population of NSW demand will increase. Therefore training provision and placement assistance needs to be included as part of this planning.

- *Genetic Data and profiling*: We recommend that the Plan acknowledges that this technology and knowledge will
 - (a) place increasing demands on testing and storage facilities. (p. 17)
 - (b) become an integral part of future research capacity (p. 16)
 - (c) recognise that use of this data requires consent and understanding, therefore education for people in firstly understanding the immediate implications for treatment and outcomes, and secondly, understanding of future use of donated tissue.
 - (d) note the need for legal provisions for knowledge of familial genetics and adequate psychological support
- *Infrastructure and Equipment* provision, update and maintenance needs also to be included in the planning for the future of NSW cancer services.
- *Research capacity*: ensure
 - (a) consumer input into research proposals and funding decisions
 - (b) collaboration between data, tissue banks and infrastructure sharing
- *Glossary*: The definition of palliative care is not accurate and reflects the American view, not the Australian one. Palliative care may be used at stages of the cancer journey which are not necessarily regarded as “end of life”. NSW health pillars: this definition is too vague – the four “pillars” should be named.
- *Commitment to consumer engagement*: it is imperative that the Plan recognises that CINSW and other relevant agencies have a commitment to consumer engagement (which most do), and that they will respond to consumer initiatives, as they have done successfully, and in partnership, in the past. Reference: *Cancer Australia/ Cancer Voices Australia National Framework 2011*.
- *Performance Index*: Cancer Voices was very impressed by the keynote address of Pro Tom Feeley (MD Anderson and Harvard Business School) at CINSW’s Innovations Conference on 15 October. His message was that *outcome* performance measures are essential for achieving an efficient and effective cancer service, anywhere. NSW Cancer Plan readers will be most interested to turn to the section titled “Performance index – Indicators” (pages 20 and 21). However we are concerned that they could get a rather unbalanced view of what we are trying to achieve in NSW. Again there is heavy emphasis on very few cancers or conditions under “Improve cancer outcomes”. Here Cancer Voices would like to see the following incorporated into the Performance Index, and by cancer type, at say 2010, 2015, 2020:
 - No. of patients treated on time and according to guidelines (EviQ et al)
 - No. of patients receiving multidisciplinary, coordinated cancer care (planned to be recorded by Health e-Net, the e-health system for NSW)
 - Statistics showing longer survival post initial diagnosis (post 5, 10, 20 years)
 - Statistics showing fewer metastases diagnosed (Clinical Cancer Registry)
 - Statistics showing number of metastases treated (“ “ “)
 - Statistics showing how NSW hospitals treating cancer measure up in regular NHPA and other performance studies, and what happens regarding the outliers.
 - Utilise cancer health care complaint data to track and improve service. Set performance levels to assist with highlighting areas of need. This would provide a number based system of service satisfaction (p. 21).

Concluding Comment

These are important issues. We recommend that it is imperative that they are noted and that actions to address them should be included in a document with the title "NSW Cancer Plan", especially under "prioritised issues" (pages 15-18). Like the CINSW itself, we within Cancer Voices, aim for better outcomes and experiences for all NSW cancer patients. We would feel more comfortable if the NSW Cancer Plan reflected this objective more clearly.

While some of the goals we recommend above for inclusion in the NSW Cancer Plan may not be fully attainable during the Plan's life, we ask that they be included as goals to work *towards*, and identified as such. A Plan is not much help if it only addresses those things which can be done now or in the next few years.

We note the compelling message given at the Cancer Institute's Innovations Conference on 15 October, which a number of Cancer Voices NSW members attended. Prof Tom Feeley emphasised that we in NSW should strive to measure patient outcomes, not episodes of care. We need to know which cancer centres, public and private, are delivering the best outcomes across the continuum of care; and this should be publicly reported. The only publicly reported measured outcomes we are aware of now are cancer surgery waiting times by hospital for three selected cancers (breast colorectal and lung), delivered to us by the National Health Performance Authority. These identify outliers which is a useful planning tool, but for only one episode of care.

We live in a big data era, so the void of up to date data and data about recurrences, metastases, and treatment outcomes seems inexcusable. Consider what business does; even the smallest companies can see how much stock they currently sell, compare themselves to cohorts, review history and predict trends for planning. Why is this not the case in cancer care, or at least a goal within a statewide cancer plan?

Other CINSW Innovations Conference speakers supported this call for collection of good outcome data via electronic records, noting that the advent of electronic technology enables us to generate data to drive reform of our existing system. One stated that our present system as "fragmented and outcomes blind". We must be able to do better, and we people affected by cancer turn to the Cancer Institute NSW to lead the way. The NSW Cancer Plan 2016-2020 is the opportunity to do this.

Please accept these comments in lieu of a survey response. Obviously we have taken the invitation to respond very seriously and trust that our comments are received in a like manner. We plan to post this submission on our website.

Yours sincerely



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Chair, Cancer Voices NSW

29 October 2015