Cancer Council NSW Submission to Draft NSW Cancer Plan 2016-2020

Note: Input (via online questionnaire), October 2015

Do you have any comments or feedback about the introductory section of the NSW Cancer Plan 2016-2020 (p3-10)?

Page 7: The major achievement's section of the NSW Cancer Plan 2011-2015 includes the implementation of the NSW Skin Cancer Prevention Strategy in which CCNSW is a lead agency in a number of prioritised actions. This has been a positive example of consultation and collaboration across numerous stakeholders and this type of framework/partnership could be built on in other areas, such as cancer support services, in the next Cancer Plan.

Page 8: CCNSW is pleased to see the draft Plan encompasses the role of many partners and organisations, including NGOs like CCNSW. We suggest that on page 8, the statement 'This plan, has been developed as an across-Government, statewide plan' may benefit from the addition of 'across non-government'.

P10: Key focus populations: CCNSW welcomes the recognition of the unequal distribution of the impact of cancer on Aboriginal communities, culturally and linguistically diverse communities (CALD), those from lower socio-economic backgrounds and those from regional and remote communities. Referenced data has only been provided for Aboriginal communities and CALD communities so the inclusion of referenced data about regional and remote communities and disadvantaged socio-economic communities would be beneficial.

P10: Key focus cancers: A brief explanation of the reason for focusing on lung, colorectal and primary liver cancers would be helpful to allow the diverse readership to understand the selection criteria used.

The three dot points appear inconsistent in referencing current evidence. For example there is data about: deaths/week for colorectal cancer only; the causes of the increased incidence in primary liver cancer only. It may be useful to include the factors contributing to the increase in the incidence of primary liver cancer, and in the other dot points. The dot point about liver cancer notes that incidence rates have 'increased significantly over the last 10 years' but it may be more impactful to include by how much.

The dot point about colorectal cancer refers only to early detection as a way of reducing the incidence. It may be useful to include preventive strategies such as promoting changes in lifestyle behaviours. Evidence highlighting the associations between food, nutrition, physical activity and colorectal cancers is available in the World Cancer Research Fund Colorectal Cancer 2011 Report http://www.wcrf.org/sites/default/files/Colorectal-Cancer-2011-Report.pdf. David Whiteman et al have also developed preventability estimates about lifestyle factors and their association with bowel cancer cases in Australia see Australian and New Zealand Journal of Public Health Oct 2015 http://onlinelibrary.wiley.com/doi/10.1111/azph.2015.39.issue-5/issuetoc

Page 11: Key health care systems of focus: The addition of a cancer pathway graphic is positive although it may need an arrow to show that, for some cancers such as melanoma, there is no screening program/process so the pathway bypasses that box. The pathway includes prevention through to recovery/survivorship and survivorship/end of life. However, the systems named underneath are limited to Primary health care and Patient-centred, quality cancer health care. These systems are not inclusive of the number of non-clinical services provided, particularly those for cancer prevention and early detection. The addition of "community settings and services" as a third system that underpins the cancer pathway may add clarity.

The inclusion of a 'rapid learning system' is positive, and would be enhanced if the meaning of the term is clarified. The boxed section includes a statement but it is only the title of the reference that mentions the term. This could be easily remedied by adding a title of 'definition' in the box. Also using a definition that focuses only on information obtained in the course of clinical practice may be limiting. It may benefit from the inclusion of prevention (for example which is particularly relevant to reducing overexposure to the sun), and information and support. This section refers to improving cancer care for people affected by cancer. For many, it may not be apparent that the term cancer care includes end-of-life palliative care that is provided after active treatment of cancer ceases. This sentence may be better to read 'cancer care, *and end of life/palliative care,* for people affected by cancer.' While the greatest opportunity for implementing a rapid learning system lies within NSW Health's clinical services this principle should not be limited to only those services.

Current technologies may enable data collection, real-time analysis and information to improve practices in smoking cessation, such as the provision of brief interventions. However smoking status is not routinely collected throughout the health care system and this should be a prioritised action in the draft Plan.

Do you have any comments or feedback about Goal 1: To reduce the incidence of cancer (p12-13)?

Tobacco control: Overall the Plan offers some positive contributions for tobacco control in comparison to previous plans. The inclusion of priority population groups with high smoking prevalence, such as people in custody and people with mental illnesses, and groups where smoking cessation could make a significant impact, such as pregnant women and people diagnosed with cancer, is positive. This expanded list recognises the significant inequalities in smoking-related harm among some population groups within our community. However, there is also evidence that smoking prevalence is significantly higher in other population groups that have not been named in the draft Plan such as: Lesbian, Gay, Bisexual, Transgender and Intersex communities; people with drug and alcohol dependencies; people experiencing homelessness; at-risk youth; and low income families, particularly single-parent families with dependent children. Some of these additional groups may be captured under socio-economically disadvantaged communities but this could be made more transparent. It may be helpful to acknowledge that the target priority populations are not exhaustive and that for the purpose of the draft Plan, certain population groups have been prioritised based on the opportunity to have the greatest impact. The NSW Tobacco Strategy and the NSW Cessation Support Services Strategic Plan will also provide opportunities to ensure that high smoking prevalence is addressed across a broader range of priority populations.

The draft Plan does not address smoke-free environments. Second-hand smoke exposure is a known carcinogen to humans and there is no safe level of exposure. Significant progress has been made to protect the NSW community in more settings, a notable example being smoke-free outdoors. However there is still much work to be done. Protecting the NSW community by: addressing gaps in existing smoke-free environments legislation including ending the 75:25 definition of enclosed spaces; having clearer definitions of outdoor dining; including e-cigarette use in smoke-free laws and enabling smoke-free protections in multi-family housing are essential strategies. An extra strategy to expand protections to second-hand smoke exposure should be included in the draft Plan. Additional legislative and regulatory change to address gaps in smoke-free environments and the introduction of legislative and regulatory changes to enable smoke-free policies across a range of multi-family housing settings should also be included as priorities for action.

The prioritised actions under 'reduce the use of tobacco and tobacco products' require some additional detail. Firstly, in addition to implementing and evaluating the NSW Tobacco Strategy 2012-2017 there should be commitment to developing a NSW Tobacco Strategy 2018-2022 under this draft Cancer Plan. The Tobacco Strategy provides the necessary detail for effective and efficient coordination and prioritisation of tobacco control activities in NSW.

It is also recommended that, in the first two prioritised actions, a clearer distinction is made between "public education campaigns that target priority populations" and "social marketing programs aimed at priority populations".

It is recommended that the Prioritised action 'deliver evidence-based, effective and efficient Quitline and iCanQuit services that focus on…' be less specific. This could be changed to 'cessation support services' which would be detailed in a NSW Cessation Support Services Strategic Plan 2016-2020. This recognises the important and much needed provision of cessation support services offered in NSW beyond the two services provided by Cancer Institute NSW. It is important that the NSW Cessation Support Service Strategic Plan 2016-2020 captures other activities such as capacity building of the workforce, for example those working in Aboriginal health, community services, general practice and prisons to deliver cessation support.

Similarly it is important to expand 'Embed brief interventions for smoking cessation in clinical care' to be more inclusive of other priority settings in which to offer brief interventions. CCNSW believes it is important to embed brief interventions for smoking cessation into community services in order to address high smoking prevalence in several of the identified target priority populations. CCNSW recognises the opportunity for significant advancements in identifying smokers, recording smoking status and offering brief interventions through the implementation of a 'rapid-learning system' within NSW Health clinical services. If this prioritised action is designed to achieve this then it may be made more explicit about and be separated from the need to embed brief interventions in other settings.

In addition to smoking cessation support services, the draft Plan should also include a prioritised action to create supportive environments for smokers attempting to quit and ex-smokers. Currently, the widespread availability of tobacco products in retail outlets is out of line with the harm caused by smoking.

The draft Plan makes no mention of electronic cigarettes, which is an important emerging tobacco control issue. The Cancer Institute, NSW Ministry of Health, smoking cessation support service providers and non-government organisations all have a role to play in generating evidence, providing advice and developing policy recommendations on electronic cigarettes. The inclusion of the use of electronic cigarettes in smoke-free public places is a particular policy gap which requires attention.

Healthy weight, diet, physical activity and alcohol: It is pleasing that the draft Plan refers to lifestyle risk factors such as unhealthy weight, poor diet physical inactivity and alcohol. The inclusion of healthy eating and prevention of overweight and obesity is positive and would benefit from more detail and clarity.

In 2013, CCNSW conducted a Community Survey on Cancer Prevention. Findings indicated that, compared to tobacco use and sun exposure, there was a lower awareness of cancer risks related to overweight and obesity, physical inactivity, insufficient fruit and vegetables and high intake red/processed meats and alcohol. Raising awareness is an important first step in cancer prevention and Cancer Institute has demonstrated leadership in raising awareness regarding tobacco and sun protection through social marketing campaigns. CCNSW would be pleased to see further social marketing campaigns focusing on raising awareness of these other lifestyle risk factors.

NSW has a Healthy Eating and Active Living (HEAL) strategy 2013-2018 which includes an objective to increase community awareness of healthy eating and physical activity as protective factors against chronic disease. Clarifying the link between the HEAL strategy and the draft Cancer Plan may be useful.

Alcohol: CCNSW is pleased to note the inclusion of a prioritised action to implement and evaluate initiatives aimed at reducing the harm associated with alcohol use across the community. CCNSW believes that initiatives focused on policy interventions related to licencing, pricing, promotion and availability will be important.

CCNSW believes that the development of a statewide alcohol harm prevention plan, as recommended by the NSW/ACT Alcohol Policy Alliance (NAAPA), will be beneficial and should be added as an extra prioritised action in the draft Cancer Plan. It would provide a strong framework for

the next action which is to implement and evaluate initiatives aimed at reducing the harm associated with alcohol use across the community.

Other preventable cancers: CCNSW believes that Goal 1 will benefit from inclusion of prevention strategies such as: cancer vaccines for cervical and liver cancer; chemoprevention for colorectal cancer; aspirin and antiviral medications for primary liver cancer. There is evidence that Australia two-thirds of liver cancers are caused by chronic viral hepatitis and that outcomes have not improved significantly using conventional oncological approaches. Most primary liver cancers are preventable and the best value for money arises from prevention strategies. Therefore inclusion of an objective specifically related to reducing the risk of viral hepatitis and a strategy about chemoprevention should be included.

Do you have any comments or feedback about Goal 2: To improve the survival of people with cancer (p14-16)?

P15

CCNSW believes that the first objective would benefit from the inclusion of an additional strategy and actions to support the transition to 5-yearly HPV screening, through the upcoming Renewal of the National Cervical Screening Program in 2017. Actions may include: develop comprehensive social marketing and GP educational programs to support the transition of the screening program. Another action may be to develop materials explaining the Renewal's integrated approach to HPV vaccination and HPV screening, the complementary nature of these interventions and the continuing need for women to be screened even if vaccinated. Another important action includes supporting the implementation of HPV self-sampling strategies as a key aspect of the Renewal, in order to increase cervical screening participation in under-screened populations, in particular Aboriginal women.

Under the second objective the strategy to 'facilitate the earlier detections of cancers' includes an action about monitoring of people at risk of cancer due to lifestyle or other factors. Greater clarity and specificity may be required for this action, particularly for the key focus cancers identified in the draft Plan. The strategy to 'strengthen the capacity of the cancer system to deliver patient-centred, integrated, multidisciplinary and quality care' is acknowledged as a positive inclusion.

In relation to liver cancer, the Plan may also benefit from defining how integration with chronic disease management and viral hepatitis strategies will occur.

P16

The inclusion of an action to 'expand access to and use of cancer-relevant data' is positive. However to ensure this happens, up-to-date cancer registries and population-level data is essential. This will require regular updating of the NSW Cancer Registry and ensuring that clinical data is shared with researchers, non-government organisations and service providers in a timely manner. This underpins a 'rapid learning system' and it will assist with more transparent monitoring and evaluation processes. The Plan could include actions that address these problems.

CCNSW welcomes the renewed focus on clinical trials and recommends developing an expanded set of Performance Indicators for clinical trials that address the complexities of trials rather than just the number of participants. This includes trials addressing rare cancers. CCNSW looks forward to more detail of the scope of the clinical trials program and whether Phase 1 trials will be included in the future, and an assessment of whether trials assessing the utility of pharmacogenomics and biomarkers will qualify for inclusion in the new Clinical Trials Program.

This goal would also benefit from inclusion of strategies that relate to early detection of melanoma and skin cancer, and reference to new developments in lung cancer screening that are likely to impact practice. The role of personalised medicine, the impact of recent major advances in the treatment of

melanoma and lung cancer on patient outcomes and costs, and addressing workforce issues also need to be addressed under this goal.

The strategy 'build globally relevant cancer research capacity' may benefit from the addition of actions to: facilitate increased access to population registries as a means of recruitment to studies and clinical trials of primary and secondary prevention strategies; and 'invest in systems for increasing researcher utilisation of routinely collected population data, to facilitate ongoing assessment of the effectiveness and cost-effectiveness of primary and secondary prevention strategies, and diagnostic and cancer treatment strategies.'

Do you have any comments or feedback about Goal 3: To improve the quality of life of people with cancer (p17-18)?

P18
The Goal (to improve the quality of life of people with cancer) and the objective (enhance the experiences of people affected by cancers) are similar. Currently this goal has only one objective and the goal and objective appear similar. There may be benefit from including 2-3 objectives to reflect the complexity of this goal.

The inclusion of an action to embed interventions for smoking cessation in cancer diagnosis and treatment services is positive, and is in-line with recent evidence on the potential impact on cancer survival if smoking cessation increased among people diagnosed with cancer who continue to smoke. (Sitas F, Weber M, Egger S, et al. Smoking cessation after cancer. American Society of Clinical Oncology. 2014.)

Actions such as 'develop and disseminate information…' and 'provide accessible information and support …' are more likely to be successful through partnerships, so that existing resources and programs aren't duplicated. The draft Plan, or the subsequent implementation plan, could articulate how dissemination will occur, including engaging health professionals in the distribution of information to patients.

The previous Cancer Plan included a specific strategy about patient-centred, quality system for Aboriginal people with cancer and their carers. The draft Plan would benefit from a similar inclusion.

Do you have any comments or feedback on the implementation, monitoring and evaluation of the NSW Cancer Plan 2016-2020 (p19-21)?

Implementation

CCNSW as a co-lead: As previously discussed with the Cancer Institute, CCNSW will be pleased to take a co-lead role in the implementation and reporting on the following prioritised actions:

- Implement and evaluate the Skin Cancer Prevention Strategy 2016-2020, including social marketing programs that target priority populations.
- Implement strategies, and develop and disseminate tools and resources that support people affected by cancer to appropriately self-manage
- Provide accessible information and support to people with cancer.

In addition to the above, CCNSW is well placed to co-lead prioritised actions related to health lifestyle changes including:

- Implement and evaluate the Healthy Eating and Active Living Strategy 2013-2018.
- Implement and evaluate initiatives aimed at reducing the harm associated with alcohol use across the community. CCNSW has developed community advertisements for raising awareness about the association between alcohol and cancer association. As a co-leader CCNSW could contribute to the development and implementation of a comprehensive statewide campaign to utilise this resource.

Prevention strategies focused on preventing primary liver cancer are not currently included under Goal 1. However if there were to be included as suggested, CCNSW would be able to play a co-lead role by fostering collaborations between gastroenterologists and hepatologists who diagnose and treat most cases of liver cancer.

CCNSW as a collaborative partner agency: CCNSW is also well placed to partner on prioritised actions that relate to tobacco control, in particular:

- develop, implement and evaluate Tobacco Strategies in relation to smoke-free environments; public education campaigns; regulation of electronic cigarettes and reducing the retail availability of tobacco products and
- generate and use new evidence to inform strategic planning, and the development and implementation of tobacco control policies, projects and services

If, as suggested the following actions are included in the draft Plan, they would provide an opportunity for CCNSW to be a collaborative partner:

- embed brief interventions for smoking cessation in community settings and
- introduce legislative and regulatory changes to enable smoke-free policies across a range of multi-family housing settings.

CCNSW will be pleased to participate in discussions about co-leading and partnerships as the draft Plan is progressed and/or an implementation plan is developed.

Monitoring and Evaluation – the NSW Cancer Plan 2016-2020 Performance Index

Reduce the use of tobacco: the three Performance Indicators are appropriate and CCNSW suggests an additional indicator; 'the proportion of patients in clinical services for which smoking status is recorded and smoking cessation advice is provided'. This will reflect the draft Plan's strong focus on creating a rapid learning system and embedding brief interventions in clinical services.

Reduce over exposure to ultraviolet radiation: the three Performance Indicators are appropriate and align with the NSW Skin Cancer Prevention Strategy. The only addition suggested by CCNSW is to monitor sun protection behaviours among young people as well as adults.

Encourage health lifestyle changes and support healthy lifestyle: the Performance Indicators to measure physical activity and alcohol use are appropriate. However CCNSW believes that, alone, they are insufficient to measure healthy lifestyle changes. CCNSW recommends that Performance Indicators for weight status in the community, consumption of fruit and vegetables and dietary fibre, and the consumption of meat be included. The Cancer Institute may like to consider the addition of Performance Indicators linked to community awareness of these risk factors.

Improve cancer outcomes: The Performance Indicator 'proportion of excisions for hepatocellular carcinoma (primary liver cancer) relative to incidence' is not supported by available evidence. Findings from clinical liver cancer registries in Australia suggest that chronic viral hepatitis is responsible for over two thirds of all primary liver cancers in Australia. Therefore CCNSW suggests it be replaced with a Performance Indicator focusing on monitoring the uptake of antiviral treatment for chronic viral hepatitis.

Build globally relevant cancer research capacity: the three Performance Indicators are appropriate. CCNSW suggests that it would be beneficial to add two more Performance Indicators to this section: 'National and international competitive funding attained by NSW researchers' and the 'number of peer-reviewed publications in international journals from NSW'.

Enhance the experience of people affected by cancers: the Performance Indicator measuring the patient experience of cancer care is a positive addition but CCNSW suggests that it may be useful to include other indicators for this objective. One example may be in the area of access to information or support services. Measurements might include diversity of channels; number of local health districts disseminating information through their portals (such as Health Pathways); number of treatment centres with up-to-date patient information available for patients to self-select; percentage of newly

diagnosed patients in each treatment centre/health district receiving a relevant Information and Support Pack and referral to appropriate services/programs.

Do you have any comments or feedback overall on the NSW Cancer Plan 2016-2020?

It is positive that, as per the previous NSW Cancer Plan, the draft 2016-2020 version includes a commitment to lessening the gap for focus population groups. The draft Plan states that the needs of these communities will be addressed by specific actions (P10), however there appears to be few actions specific to the focus populations under each goal. Nor are there specific actions related to those from lower socio-economic backgrounds or disadvantaged socio-economic communities despite acknowledgement that they experience a higher incidence of cancer. The draft Plan provides an opportunity to discuss the social determinants of health that impact on cancer risks and outcomes for people from lower socio-economic backgrounds, and to develop actions accordingly. It also provides an opportunity for specific actions that involve collaboration with non-health agencies such as Department of Planning and Infrastructure, Department of Education and Communities etc.

The Cancer Plan would benefit from increasing the content about primary prevention. Discussion of the rapid-learning system could include its application throughout the cancer journey from prevention to end-of-life care. It could also include community settings and non-government service providers.

Overall the Plan could benefit from more targets and Performance Indicators, to ensure that it is clear whether the desired state-wide objectives are being achieved. In particular additional Performance Indicators for Aboriginal people, CALD background people, those living in regional and remote NSW and those from lower socio-economic backgrounds should be included to measure the experience of those affected by cancer.