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# HCCA Feedback on the ACT and NSW Health District Cancer Services Plan 2014 -2018

Submitted 23 September 2014

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## Background

The **Health Care Consumers' Association (HCCA) of the ACT** is a health promotion organisation that was incorporated in 1978 to provide a voice for consumers on local health issues and now provides opportunities for health care consumers in the ACT to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation
- consultations
- training in health rights and navigating the health system
- community forums
- information sessions about health services
- advocating for issues of concern to consumers
- works for the improvement of quality and safety of health services

## 1. General Comments

HCCA welcomes the opportunity to provide feedback on the ACT and NSW Health District Cancer Service Plan 2014 -2018. In preparing for this submission we consulted with our membership and also held a consumer consultation including a public consultation held in collaboration with ACT Health on the 10th of September 2014. This draft has been shaped by HCCA's Health Policy Steering Committee and informed by the input of; Canberra Alliance for Harm Minimisation and Advocacy (CAHMA), Cancer Council ACT, Hepatitis ACT, Canteen ACT, Bosom Buddies ACT, the ACT Palliative Care Network and the ACT Prostate Cancer Support Group.

HCCA would like to acknowledge the willingness of ACT Health to actively engage with consumers in the ACT and Southern NSW to improve care for those in our community with cancer.

On the whole, consumers, families and carers are satisfied with the provision of cancer services but there are number of concerns. This strategic document acts as a blue print that can direct cancer services to improve access to services and create a continuity of care for those accessing these services. The plan will shape a change in service delivery that allows a response to increasing demand in an efficient and sustainable way. HCCA acknowledges the commitment The ACT and NSW Government is making to address gaps in current cancer services and looks forward to seeing an effective implementation of this high level document in achieving a marked improvement to cancer services in this region.

In this submission we will provide comment on the document and its specific goals, actions and outputs and on areas of cancer services that are currently not meeting the needs of consumers, carers and families in this region. A major concern we have is that the document seems to be largely service focused rather than on improving care for users of these services. Service and planning documents need to be driven with consumers, families and carers at the centre of care.

Indicators or action measures, outputs and outcomes within the plan are very important, particularly around person-centred care. HCCA recognises the need for these measures, outputs and outcomes to be further developed throughout the implementation of this plan and emphasise the importance of continuing to partner with consumers and HCCA in the evolution of this strategy. We would like to see these indicators, actions and outputs reflect the tenants of consumer and family centred care.

HCCA is an organisational member of the International Alliance of Patient Organisations (IAPO). IAPO is a unique, global alliance representing patients of all nationalities across all disease areas and promoting patient centred healthcare around the world. We believe that consumer-centred health care can be successfully achieved through the application of five key principles as developed by IAPO:

1. Information
2. Choice and empowerment
3. Consumer involvement in health policy
4. Access and support
5. Respect

HCCA suggests that these principles, along with the Australian Charter of Health Care Rights can be used as a framework in the Plan ensure the Cancer Services Plan is truly achieving person-centred care.

## 2. Specific Comments

### Current Gaps in Cancer Services in the ACT and Southern NSW

Consumers have identified several gaps in current cancer services and patient care that are not adequately addressed in the current draft of the cancer services Plan. These relate to;

- The role of General Practitioners and Primary Health Care in providing care for consumers, carers and family

- Continuity of care and fragmentation of services, including the coordination of care for those required to travel interstate for cancer services
- Patient journey's through cancer services and expectations of treatment
- Culturally and linguistically diverse communities and marginalised groups within the ACT and NSW receiving accessible and respectful care

## The role of General Practitioners (GPs) and Primary Health Care in providing care for consumers, carers and family

GPs and primary health care play a critical role in the Australian health care system. Whilst some cancer services consumers feel that their GP is key to their care, for many timely diagnosis and investigation of their symptoms by GPs, as well as the role of GPs in continued care management, was a key area where current ACT region cancer services needs improvement. This is consistent with research that shows cancer patients are often unsure of what role GPs play in continuing cancer care after diagnosis, noting that poor communication between the GP, patient, families, carers and the treatment team was often a major problem[1].

Halkett, Jiwa & Lobb (2014)[1] also found that many consumers with advance cancer diagnoses wanted their GP to be an advocate for their wishes and help support their family and carers. Many consumers tells us that there is no effective feedback loop or communication between GPs and their treating team meaning people can slip through gaps and not be provided timely care. This role could be played by another member of a primary health care team such as a nurse practitioner trained in care for those with cancer.

> *"My dream is that I could have a helicopter nurse practitioner, who would be able to facilitate and coordinate my care as I lose the ability to manage all of my conditions. I would like this to be one of the roles of a nurse practitioner" – HCCA consumer representative with multiple chronic conditions.*

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[1] Halkett, G.K.B., Jiwa, M. and Lobb, E.A. (2014), Patients' perspectives on the role of their general practitioner after receiving an advanced cancer diagnosis. European Journal of Cancer Care. doi: 10.1111/ecc.12224

The value of primary health care teams in the patient journey of someone with cancer is becoming increasingly more relevant as people begin to present with multiple co-morbidities. General Practice needs to support to take on this role. Cancer Australia has recognised this and developed a number of specific initiatives to build capacity of general practice to play and enhanced role in primary care[2].

HCCA would like to see a clear section in the Plan around the role primary health care plays in providing cancer services and how it will be supported, including a description of the role the newly established Primary Health Networks could play in ensuring integrated and seamless care for cancer services consumers and their families and carers. HCCA also would like to see a more detailed paragraph on how the Plan will help coordinate the interactions of public and private cancer service providers to ensure care is seamless for patients, families and carers.

## Continuity of care and fragmentation of services, including the coordination of care for those required to travel interstate for cancer services

For many consumers of cancer services in the ACT region the experience of fragmented health care is all too common. We note that the current draft Cancer Services Plan does detail current services and is looking to address this issue. As the ACT region is too small to support a large number of cancer specialists it is often necessary for cancer patients and their families and carers to travel interstate to receive treatment. We accept this approach for service delivery, however it is important to have key messages around this model to share with the community so we know what to expect.

It is essential that the Plan clearly outlines how the ACT and NSW Government intend to coordinate care and support these consumers and their families as they move between local and interstate services and how it can be ensured that people who do receive treatment from treating teams locally and interstate have seamless holistic care, with coordination of both treating teams and services.

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[2] Cancer Australia (2012) Accessed on 20th September: http://canceraustralia.gov.au/clinical-best-practice/cancer-learning/general-practice-and-cancer-care

These experiences is particularly true for young people with who cannot receive specialist cancer treatment in the ACT and surrounding regions.

> *“How will this Plan help youth and young people with cancer? I know of a 13 year old girl who has had to spend the last 9 months in Sydney to receive treatment. Her whole family are squeezed into a one bedroom Ronald MacDonald House.” – Worker from Canteen Community Consultation on Cancer Services Plan 10 September 2014*

We also suggest including a section on how consumers of cancer services and their families and carers can be assured access to transport that allows them to receive care, particularly those travelling from rural NSW or coastal areas to receive care in the ACT. Transport is often dismissed as a trivial issue when looking at health services but is a major barrier for many in receiving timely care. For this reason it is essential that the Plan dictates how the ACT and NSW Government aim to provide adequate transport for those using, or supporting someone to use, cancer services.

HCCA would also like the Plan to look at accommodation for those travelling to receive cancer treatment. HCCA is aware that Duffy House is available for those who are receiving cancer treatment in the ACT and would like to see the Plan articulate how Duffy House will be used in this new service model and asks for regular reporting on the current use of Duffy House and any other accommodation currently being used for cancer services consumers and their families and carers.

## Patient journeys through cancer services and expectations of treatment

The experience of cancer and cancer treatment is often extremely variable between individuals receiving care. Whilst care should be flexible enough to meet the needs and choices of individuals, unnecessary variation in cancer treatment plans and referral pathways within cancer services not only makes it hard for consumers, families and carers to navigate cancer We are also Concerned that this could expose consumers to risks and poor health outcomes.

The introduction of clear treatment pathways like those seen in *HealthPathways* which is currently being introduced and has been shown to make significant improvement in the way primary health care teams, allied health teams and hospitals provide care and improve patient outcomes. We are very keen for the Cancer Services Plan to include reference to *HealthPathways*. We accept that it is early stage of development in the ACT and SENSW, but this will significantly change the way in which care is provided and must be factored into the current draft of the Plan. We particularly draw your attention to South Australia Health work on cancer care pathways[3]. This program will go some way to increase the capacity of general practice to further develop a role in the provision of cancer care.

Consumers, families and carers also benefit from increased knowledge and understanding of what they can expect in their whole cancer journey. This not only allows them to make informed choices about their care but also allows them to assess if their treatment is meeting their needs and expectations. In response to this need HCCA would like to see the Cancer Services Plan clearly articulate goals and action to increase community health literacy about cancer and cancer treatment as a means for consumer empowerment and better health outcomes.

Health literacy is a focus of HCCA, and our work in this area is based on the understanding that health outcomes are better when consumers have good health literacy and when health services, activities and support groups have inclusive policies and practices[4]. The Health Literacy program enables disadvantaged and marginalised health consumers to build skills and knowledge to improve their use, understanding, awareness and confidence engaging with their own health, their families health and with support services, community services and with the health system. The link

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[3] South Australia Health (May 2014) Accessed on 20 September 2014 :http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/clinical+resources/clinical+topics/cancer+and+oncology/cancer+care+pathways

[4] Australian Primary Health Care Research Institute (APHCRI) Video Interview *The role of primary health care in the context of the larger health system Dr Dr Hernan Montenegro, Health Systems Advisor at World Health Organization* accessed May 2014-http://www.youtube.com/watch?v=FHAwMo_8Q5E

between health literacy and better health outcomes is well established[5]. Developing strategies to reduce the effects of low health literacy on health outcomes warrants the attention of policymakers, clinicians, and the community.

## Culturally and linguistically diverse communities (CALD) and marginalised groups within the ACT and NSW receiving accessible and respectful care

HCCA notes that despite clearly stating the relatively high percentage of CALD community members in the ACT and surrounding areas, the Plan does not include specific actions or goals around ensuring access to CALD and / or marginalised or vulnerable groups in this region. This must be addressed to ensure that subsequent models-of care and changes to services are sensitive to the needs of these members of the community. Consideration of CALD community needs in health service provision is a requirement as stipulated in the ACT Health Multicultural Coordinating Framework[6].

> *'All Authors of policy and strategic framework documents consider and are provided with advice on potential CALD impacts'*- Key Action Areas (Section 6.1.2) ACT Health Multicultural Coordinating Framework 2014 -2018

HCCA recommends the Cancer Services Plan uses Federation of Ethnic Communities' Councils of Australia 2010 report on Cancer and Culturally and Linguistically Diverse Communities as a resource to develop a section in the Plan that outlines CALD community engagement and access to cancer services[7]. The Cancer Council of NSW has also developed resources and research on CALD communities and cancer services[8] which could be used in the Cancer Services Plan.

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[5] Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low Health Literacy and Health Outcomes: An Updated Systematic Review. Ann Intern Med. 2011;155:97-107.

[6] ACT Health (2014)*, Health Multicultural Coordinating Framework 2014-2018*

[7] Federation of Ethnic Communities' Councils of Australia (2010*) Cancer and Culturally and Linguistically Diverse Communities*

[8] Cancer Council NSW (2014) *Cancer issues across the language divide* Accessed on 18 September 2014 :http://www.cancercouncil.com.au/65792/uncategorized/cancer-issues-across-the-language-divide/

HCCA would also like the plan to address the effect of stigma on patients receiving treatment for cancers often associated with drug and alcohol use such as liver and lung cancer. HCCA has heard anecdotally that it can be difficult to receive respectful care for those who state they are current or past drug users effecting their access and ongoing treatment. This issue must be addressed as liver cancer continues to rise in the ACT region. The following quotes and question are from the community consultation on the Cancer Services Plan made by representatives of Canberra Alliance for Harm Minimisation and Advocacy (CAHMA) an organisational member of HCCA. We ask that these questions be addressed in the Plan or if not included then feedback on reasons for this to be provided to HCCA:

> *Liver disease is a leading to cancer is massively undertreated. Liver Cancer from hepatitis is 98% avoidable. How does this fit into a Plan such as this? – CAHMA representative Community Consultation on Cancer Service Plan*

> *'What steps can we take to ensure highly marginalised people are included at every stage?- i.e the population that does not access primary health care' – CAHMA representative Community Consultation on Cancer Service Plan*

> *'BIG ISSUE OF ACCESS TO PAIN RELIEF (SIC) –"Palliative care" is trotted out as a solution for all needs for proper pain management. Due to the "war on people who use drugs" many people have huge problems accessing pain relief even with cancer due to having been in the past, or being a current drug user. This is unacceptable.' – CAHMA representative Community Consultation on Cancer Service Plan*

> *'PREVENTION should be a focus. LIVER CANCER. (SIC) Rates of liver cancer are increasing due to untreated Hepatitis C. Currently the liver clinic acts as a 'gatekeeper' to hep c treatment. Many past/ current drug users get told to "come back in a few years" this is potentially a death sentence. Issues like this must be fixed or liver cancer deaths will continue to increase.' – CAHMA representative Community Consultation on Cancer Service Plan*

Further consideration of issues for marginalised communities is needed in the next iteration of the draft. HCCA would like the Plan to address how it will ensure access and respectful treatment to marginalised groups throughout the entire continuum of cancer services, particularly given that many of these groups do not have access to a regular GP.

## 3. Feedback on Cancer Services Strategic Plan document

Whilst HCCA acknowledges the effort the current Plan makes to address issues in current service provision the document itself lacks clarity as to who the audience of the Plan is, what is covered, or a clearly flagged description of the scope of this document. It is not easily accessible to consumers and seems to be more focused on service providers rather than consumers and families. These internal inconsistencies make the Plan difficult to navigate and to see how outcomes can be achieved or how this document will improve patient outcomes. Whilst aspirational goals are important when envisioning flawless cancer care, without clear and achievable, measures and outcomes it is impossible to achieve change or indeed to measure any change there may have been.

### Language in the document, vision and goals

Both the vision and goals of the Plan seen on page seven could be rearranged to strengthen the commitment of the ACT and NSW Government to person-centered care. The current draft focuses on improvement of services and research from a service perspective. Whilst this is clearly key to quality and safe care, this should be to support and drive the ultimate goal of an improved experience and health outcomes in relation to cancer for people in this region. As such by bringing these end sentences to the start of each paragraph the Plan becomes more clearly driven by person-centered goals. We suggest revision of the vision to read;

> *People from ACT and SNSW LHD have improved experiences and health outcomes in relation to cancer, and have access to equitable and timely care,*

> *including high quality preventative, early diagnosis, cancer care and support services.*

The strategic service goal can likewise be amended to read;

*People from ACT and SNSW LHD experience seamless services along their cancer patient journey, receiving care evidence-based care from a leading regional service of excellence with strong connections to high quality research.*

The language of the 'four pillars' of service delivery is an expression that is confusing for consumers and lacks clarity of how these principles frame the goals of the document. The pillars 'converge' on page 24 which needs to be addressed to present a stable structure within which care is delivered. Changing the word 'pillars' to principles may help clarify the document. HCCA also recommends that patient-centered not be one of the four principles but an overarching governing principle that drives the entire purpose of the Cancer Services Plan, distinct from the others which are all outcomes of successful person-centered health care. If this is not feasible then HCCA suggests at minimum that person-centered is placed first in the list of principles.

Along with the vision, goal and principles it would be useful to articulate the audience for this Plan. Feedback from members was that this needed to be clearer: is the document for, consumers, carers and families? Service Providers? Community Groups? Or other key stakeholders? HCCA has long argued that for publications that meet the specific needs of consumers and the broader community. One way this could be achieved is by adopting the 1:3:25 approach used by some universities. In this approach one page is used to identify key messages or an overview for the community and three pages are used to provide more detail, much like an executive summary, this could be written by experts and community representation. Twenty-five pages are then used for technical and detailed aspects of the document with goals, indicators, outputs and outcomes.

HCCA has also received the suggestion that an the Plan could be turned into an interactive infographic that consumers and the community could use to look at the

Plan in detail and think about possible ways to help implement and interact with the Plan.

It would be of value to include a glossary or definitions of terms as the Plan often uses acronyms that are not clearly defined in the document. A list of key stakeholders and who this refers to would also be helpful. For instance does the word consumer in this Plan refer specifically to those who are currently receiving cancer treatment or is it inclusive of consumer support groups and advocates?

On page 17 of the current draft of the Cancer Services Plan, HCCA suggests a revision of language, changing the phrase *patients will live longer* to *people will live longer,* As people are more than just patients.

### Defining the scope of the Plan

HCCA would like the Plan to expand the first paragraph on page seven to clearly explain how the Plan will coordinated and work with private cancer services providers to ensure seamless and high quality care to patients, families and carers.

The role of community groups is not articulated in the Plan despite the fact this can play a huge role in supporting consumers. For example,e Bosom Buddies ACT, who support women who have breast cancer, or the Prostate Cancer Support Group.

HCCA also notes there are only two references to culturally and linguistically diverse communities and no specific goals or actions in the Plan in regards to ensuring this group which makes up 20% of the ACT region community, is linked in with cancer services. We see this as a major flaw within the document that must be addressed.

> *‘What steps can we take to ensure that marginalised people and people from CALD backgrounds are included at every stage?- i.e the population that may not access primary health care’ – Consumer from Cancer Services Community Consultation 10th September 2014*

It would be of value to include example consumer stories or experiences when using cancer services in the ACT and Southern NSW and how this strategic plan may influence their journey through the system and possibly improve their outcomes or care. This again helps navigate the document, making it easy for people to connect these directions to solid action and impacts.

We understand that Project Venturi has undertaken work mapping patient journeys through The Canberra Hospital, and would be interested to know if this has informed the development of the current draft of the Cancer Services Plan.

## Context

When describing the context of Plan on page nine we suggest a longer introductory paragraph, clearly articulating how the Plan will interact with cross jurisdictional evidence, policy directions and plans. This includes describing which documents must be read together, and identifying any points that diverge in current Plan from current strategic directions. In this section it would also be useful to clearly articulate the relationship of this Plan to *HealthPathways* currently being introduced into the ACT and Southern NSW. This is particularly important given the goals of the cancer service to *create integrated and seamless care*.

## Rehabilitation services and palliative care

HCCA is pleased to see that the Plan is looking at the increasing demand for rehabilitation services with the ACT and surround regions particularly for those people who have survived their cancer. In this section of the Plan we suggest you state the relationship cancer services will have with the newly proposed University of Canberra Public Hospital, which will provide sub-acute care to this region. It would be useful to see how the model of care for this proposed rehabilitation service will be impacted by the Cancer Services Plan. The Plan also explores the provision of palliative care services to the ACT and Southern NSW region, stating;

> *‘ The ACT and surrounding regions have a limited workforce pool due to a combination of a lack of local University courses, limited University places and*

> *limited clinical training places [in palliative care].' – Page 18, Draft ACT and NSW Health District Cancer Service Plan 2014 -2018*

HCCA strongly believes this issue can be addressed by the inclusion of palliative care services at the proposed sub-acute centre on the University of Canberra campus. This will also help achieve a more integrated service for people with cancer in the ACT and surrounding area. WE have advocated for the inclusion of inpatient palliative care services in our response to the Service Delivery Plan for UCPH.

## Issues identified by stakeholders

When looking at *Table 1: Issues Identified By Stakeholders* many consumers we consulted stated that the use of the term *information* was confusing and is used interchangeably when talking about patient information and health literacy and ICT support services.

## Research

Research and evidence-based care is crucial to high quality and safe services for health care consumers. HCCA suggests the Plan outlines how the community and consumers can be involved in directing research directions for biomedical and clinic research into cancer and research on public health and service provision.

There is increasing recognition that consumer participation increases the relevance, quality and impact of health research and subsequent health policy[9]. We advocate for the inclusion of consumers in developing and participating in research. There is a growing body of evidence that recognises that partnerships between health care providers, health care professionals, patients, family members, carers and communities have a significant impact on patient outcomes and safety[10]. The

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[9] *Blignault I, Aspinall D, Barron A, McDonnell L, Reath J, Thomas R, Yates R, Wickens A. (2014). Consumer-led research in primary health care. In: 2014 Primary Health Care Research Conference: Program & Abstracts. Primary Health Care Research and Information Service, Australia. phcris.org.au/conference/abstract/7964*

[10] Australian Commission on Safety and Quality in Health Care (ACSQHC) (September 2011), National Safety and Quality Health Service Standards. ACSQHC, Sydney

importance of such partnerships is reflected in the Australian Safety and Quality Framework for Health Care[11]. By acknowledging and investigating the role the relationships of health care providers, researchers and professionals, patients, family members, carers and communities in ensuring patient safety, we deepen our knowledge of what constitutes appropriate patient care in the 21st century.

There are three tiers of consumer engagement in decisions about our health care. Firstly, individual health professionals can engage with patients to ensure they are delivering patient-centred care. Secondly, health services can partner with users of their services to ensure they are meeting their needs. Thirdly, government can engage with the community to ensure the public dollar is being spent appropriately and they are accountable for the decisions being made about our health. This move towards active consumer engagement is the most cost effective way to design, change and deliver health care as it is responsive to the needs of the ultimate end users.

It is important that when describing key features of an effective regional cancer service there is a dot point that states, patients, families and carers are central to their treatment team and are empowered to make decisions about their care. The first dot point under *service providers and policy makers* should be a strong commitment to partnering with consumers, families and carers to deliver person-centered care as this is central to an effective service.

## Directions for the future

On page 24 the Plan states that decisions regarding the implementation of the Plan need to be made on '*evidence regarding cost effectiveness and financially sustainable services'.* The draft Plan does not clearly stipulate at this point and we would like to know, who makes these decisions, how these decisions will be made and what consumer and community input can occur when this process occurs.

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[11] Australian Commission on Safety and Quality in Health Care (ACSQHC). Australian Charter for Health care rights. Sydney :ACSQHC, 2008

> *'Who will have ownership of the Plan? Who will direct it and how? How directive will it be? Will it control funding and what gets funding?' – Consumer from Cancer Services Community Consultation 10th September 2014*

**Outcomes framework**

In section 5.2 it is vital that one of the key outcomes not only focuses improved outcomes but also reflects improved patient journeys and person-centred care.

**Figure 7: ACT and southern NSW LHD cancer services outcomes framework**

Several consumers have expressed concern about Figure 7: ACT and Southern NSW LHD Cancer Services Outcomes Framework. This includes comments regarding vision and goals as previously stated in this feedback and the lack of clarity around *outcome areas* and *key enablers*. HCCA has consulted with Cancer Council ACT and supports their recommend draft framework in-terms of content and restructure. Further comments on Figure 7 as provided at the community consultation on the 10th of September can be seen below:

> *'C2 – to have personalised care it is essential that you spilt " support patient choices" from "Seamless Care" as these are separate concepts' – Consumer from Cancer Services Community Consultation 10th September 2014*

> *'B2 – when looking at access and cost of care –( not necessarily at ACT government issue) Transparency in out-of-pocket-costs is important to consumers –people have been told that out-of-pocket-costs will be around 7,000 and up with a cost of 11,000' – Consumer from Cancer Services Community Consultation 10th September 2014*

> *'Integration in this document seems to only relate to the integration of cancer clinicians rather than real multidisciplinary whole person approach - multiple conditions' – Consumer from Cancer Services Community Consultation 10th September 2014*

> *'Integration – treat who person not the cancer people undergoing chemo need special care if attending the emergency department. The cancer clinic seems to be a silo and ED does not know what medication a person on this needs to be a specific action.'* – Consumer from Cancer Services Community Consultation 10th September 2014 (This quote very confusing – not sure how to fix it!)

> *'Given that we are already in September perhaps the Plan needs to be 2015-2019 Plan'* – Consumer from Cancer Services Community Consultation 10th September 2014

## Section 6 Implementation and Monitoring

### Implementation and action plan

HCCA has major concerns about the action plan seen in Table 2. We acknowledge that this aspect of the Plan is iterative, however the lack of clear achievable outcomes and measurable outputs makes it difficult to envisage how this Plan can have any impact on improving cancer services in this region. In part we consider the absence of a clear vision to have contributed to this. This is particularly evident when looking at actions, outputs, and outcomes relating to consumers, families and carers. It is essential that every action has an outcome measure that accurately measures the success or failure to achieve these actions. As mentioned HCCA would welcome the opportunity to have continued involvement in the evolution of this strategy and the creation of goals and actions as specified by those using this service. Specific feedback on the action plan is listed below:

- The document often contains measures or outputs in the specific action column. This makes it harder to identify the effect on the consumer/patient and therefore to measure it. e.g. In A3 the action is to "Record patient journeys"- and " to evaluate patient experiences and address identified gaps" should be either a process measure or an output, depending how you express it. There should be an outcome recording the contribution of these actions and outputs to *patient* outcomes, not just to efficiency.

- In A3 it would be clearer to include an action that states *To ensure referrals between ACT and NSW clinicians are appropriate and timely and to identify and address the issues when this does not occur*

- In A2, the actions to *ensure clinical network maintains a regional focus and mandate***,** and to *put in place arrangements to ensure continued access to an appropriate range of services to the population of SNSW LHD***,** do not appear to have either an output or an outcome relating to the consumers/ patients. The one outcomes stated *-improved sense of connection etc*.**-** is a process outcome for the medical staff. There needs to be a stated outcome for patients, and also for the health system.

- A4 is well articulated, but could also include an action around consumer satisfaction with telehealth, booking and IT records systems.

- Goal B – ACCESS. B1 is about delivery of *high quality and safe services*, but the actions, measures, outputs and outcomes don't refer to either quality or safety and how to ensure it. This is a crucial intention/objective for consumers and needs to be more explicit as to quality and safety actions and measures. The outcomes measure should include reductions in mortality and morbidity as well as incidence, under prevention, screening, and treatment sections.

- B1(b) is another example where the action includes the outcome – *to reduce morbidity and mortality.*

- In B1 (c) intended reductions in morbidity and mortality are in the specific actions when it should be an outcome. These outcome reductions are critical for the consumers of cancer services.

- There should be a specific output concerning patient experience of surgery being an integral part of care plans.

- In B1 (d*) to improve quality of life for patients who survive cancer and improvements in morbidity/mortality* are important consumer outcomes, not specific actions, and enhanced "*supportive care services etc..."* are outputs for consumers not process measures.

- In B1 (e) We suggest an output measure around increased use of palliative care services by patients with incurable cancer.

- In B3: "*developing a methodology to quantify the reduction of visits..."* is a process measure (not an output measure).

- B3, There should be an output measure of "reduced visits to hospitals by rural patients because of increased use of telehealth".

- B4: It is important for consumers that there be an output measure of "*improved efficiency without reduced services (quality, safety, access) to consumers (patients, carers and families)*".

- C1: There should be a (c) which covers a specific action to evaluate consumer input (quality and effect) to various forums/networks.

- C2: There should be a process measure relating to evaluation of patient families and carer experiences of the seamlessness of services, and the extent to which the choices of patients, families and carers have been met. The output from such an evaluation should be the identification of gaps or problems with seamlessness or choice recognition.

- 12. C3 (a) An output measure is needed along the lines of *"patients, families and carers are better able to self-navigate the system"* Possibly evaluated by surveys or patient experience trackers.

- 13. C4 (b): An output should be the better identification of issues and problems for patients, families and carers.

## Evaluation and monitoring

As this plan is implemented HCCA recommends that evaluation and monitoring of this process and actions be made readily available to the ACT and Southern NSW community. This not only allows for transparency in the governance, direction and effectiveness of this document but also allows for consumers and the members of the community to actively participate in the iterative process of improving cancer services in this region. This Plan is of great interest to the community and HCCA recommends public reports on the Plan to be made at the Legislative Assembly every six months.

## Concluding remarks

HCCA would once again like to acknowledge the work of the ACT and NSW Government in developing a Plan to help address current deficiencies in cancer services in this region. The implementation of this Plan provides a great opportunity to improve the experience of people using cancer services, their families and carers.

We look forward to a response to our feedback of this document and welcome any further involvement in the implementation and continuous evaluation of this Plan.

Please do not hesitate to contact us if you wish to discuss our submission further.

## References

ACT Health (2014), *Health Multicultural Coordinating Framework* 2014-2018

Australian Commission on Safety and Quality in Health Care (ACSQHC) (September 2011*), National Safety and Quality Health Service Standards*. ACSQHC, Sydney

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