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HCCA Feedback on the ACT Lymphoedema Services Background Paper and Implementation Plan 2015 - 2018

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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 HCCA Feedback on the ACT Lymphoedema Services Background Paper and Implementation Plan 2015 - 2018. In preparing for this submission we consulted with interested members and held a consumer focus group on 28 January 2015 with ACT Health.

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 lymphoedema.

On the whole, we have received positive feedback regarding the Plan. This strategic document acts as a blue print that can direct lymphoedema services to improve access to services and create 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 Government is making to address gaps in current lymphoedema services and looks forward to seeing effective implementation of this high level document in achieving a marked improvement for consumers who need access to lymphoedema services in our region.

In this submission we provide comment on the document and its goals. A concern we have is that the document seems to be largely service provider focused rather than on improving care for users of these services. Service and planning documents need to be developed 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 and outputs to be further developed throughout the implementation of this plan and through the Lymphoedema Services Network 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 principles 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 to ensure that the ACT Lymphoedema Services Background Paper and Implementation Plan 2015 -2018 is truly achieving person-centred care.

We note that the Plan is a response to increased funding allocated in the most recent ACT Budget, however after speaking to our members using lymphoedema services this funding is unlikely to meet the large ongoing and projected need Along with workforce concerns this is explored in the background paper but does not seem to be addressed in full in the Plan.

2. Specific Comments

Executive Summary

In the first paragraph of the executive summary it is stated that there will not be a need to create a new plan after the current Plan expires. We would like to know why this is the case, as lymphoedema is likely to still be a growing area of need after 2018 requiring adequate resourcing and management.

The Plan also talks about consumers who travel from surrounding regions such as Southern NSW to access lymphoedema services. We would like to see outlined how the ACT Government will work with the NSW Government to ensure this plan is effective in supporting consumers who regularly travel interstate for care.

What is lymphoedema?

When discussing Lymphatic Filariasis it would be helpful to clarify that it is extremely rare in Australia and is usually only seen in those who have travelled or lived in tropical and sub-tropical areas. The condition is not caused by multiple mosquito bites, rather it is a parasitic disease caused by the pathogens, filarial nematodes *Wuchereria bancrofti*, *Brugia malayi* and *Brugia timori*.

Purpose and Scope of the Plan

In the last paragraph of the section on page 18 there is a comment that Model of Care (MoC) and Standard Operating Procedures (SOP) for clinical services relating to lymphoedema will not be monitored by those looking after the Plan. This is reasonable however we would like to know when these MoC and SOPs will be reviewed. We have heard from several members interest in providing feedback on their care and would be interested in facilitating consumer feedback on those documents.

Current Gaps in Lymphoedema Services in the ACT and Surrounding Areas

Consumers have identified several gaps in current lymphoedema services and patient care that are not adequately addressed in the current draft of the Lymphoedema Implementation 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 lymphoedema services
- Patient journeys through lymphoedema services and expectations of treatment

- Culturally and linguistically diverse communities and marginalised groups within the ACT and NSW receiving accessible, equitable and respectful care

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

GPs and other primary health care services play a critical role in the Australian health care system. Whilst some lymphoedema services' consumers feel that their GP is key to their care, while 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 lymphoedema services need improvement.

Many consumers say 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 with timely care. This role could be provided by another member of a primary health care team such as a nurse practitioner trained in care for those with lymphoedema.

“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.

HCCA would like to see a clear section in the Plan around the role primary health care plays in providing lymphoedema services and how it will be supported, including a description of the role that the newly established Primary Health Networks could play in ensuring integrated and seamless care for lymphoedema 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 lymphoedema service providers to ensure care is seamless for patients, families and carers. We note that the Plan briefly looks at the role of primary healthcare on page 39 in terms of prevention and identification, however there is value in discussing primary healthcare's

role more broadly in management of lymphoedema. A further description of how Health Pathways could be harnessed to ensure a clear role for primary care in lymphoedema would also add clarity and meet consumers' needs.

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

It is essential that the Plan clearly outlines how the ACT and NSW Government intend to coordinate care and support 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.

We also suggest including a section on how consumers of lymphoedema 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 clearly outlines how the ACT and NSW Governments aim to provide adequate transport for those using, or supporting someone to use, lymphoedema services.

Patient journeys through lymphoedema services and expectations of treatment

The experience of lymphoedema and lymphoedema 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 lymphoedema treatment plans and referral pathways within lymphoedema services makes it hard for consumers, families and carers to navigate lymphoedema care. We are also concerned that this could expose consumers to unnecessary 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 note that the Plan does make reference to HealthPathways.

Importance of community programs and services

One of the major comments from our members was to ensure that the Plan referenced the importance of community programs in supporting those with lymphoedema, for example Dragons Abreast an ACT Dragon Boating team for those living with breast cancer regularly discusses lymphoedema exercises and lymphoedema exercise classes. Others commented on the importance of hydrotherapy in lymphoedema management and requested that the plan works to ensure that community services such as hydrotherapy and exercises were included.

There was also acknowledgment that many lymphoedema support groups and resources are predominantly run for people living with breast cancer and that this is not reflective of all those who live with lymphoedema, this could be articulated when discussing equity and access to services.

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

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 Framework¹.

¹ ACT Health (2014), *Health Multicultural Coordinating Framework 2014-2018*

'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

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

Language in the document, vision and goals

To strengthen the commitment of the ACT and NSW Government to person-centered care a clear paragraph articulating this commitment is needed. The language on page 57 about patient-centered care would be a useful framework for this. The current draft focuses on improvement of services and research from a service provider 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 lymphoedema for people in this region.

There is some inconsistent referencing on page 32 of the document.

Research and Education

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 lymphoedema 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 policy². 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 safety³. The importance of such partnerships is reflected in the Australian Safety and Quality Framework for Health Care⁴. 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.

We also note that the actions under research and education are not specific to lymphoedema.

Infrastructure

As mentioned in the focus grouped held on January 28, we are interested in the relationship this Plan has with the newly developed MoC for new Health Infrastructure

² 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*

³ Australian Commission on Safety and Quality in Health Care (ACSQHC) (September 2011), National Safety and Quality Health Service Standards. ACSQHC, Sydney

⁴ Australian Commission on Safety and Quality in Health Care (ACSQHC). Australian Charter for Health care rights. Sydney :ACSQHC, 2008

Projects (HIP) in the ACT. These MoC are essential in planning space and resources to ensure they meet the needs of our community. It is crucial that high level strategic plans such as this one, which relies heavily on new infrastructure has a close working relationship with HIP MoC.

Technology

Technology clearly plays an important role in the management of lymphoedema in terms of medical treatment. Technology is also essential in providing integrated care for people with lymphoedema. The paragraph on page 43 is not specific in how ehealth will be used to facilitate the implementation of this plan in the ACT context and how patient information and records are currently being used when transferring from public to private providers or from Calvary to the Canberra Hospital.

Implementation and Evaluation

We acknowledge that this aspect of the Plan is iterative, however the lack of clear measurable outputs makes it difficult to envisage how this Plan can have any impact on improving lymphoedema services in this region. We recognise this may be the role of the soon to be established Lymphoedema Network but would like to highlight the need for specific outcome measures. It is essential that every action has an outcome measure that accurately measures the success or failure to achieve these actions.

The implementation plan is clearly laid out under each objective making it easy to navigate.

Objective six focusing on equity and access, seems to have a timeframe to begin action on these goals in 2018. We would like to know why these goals are set so late in the timeline of the plan. As this is an area highlighted as a key area of concern to be addressed it needs to be a continuous area of work from the beginning of the work of the Lymphoedema Network in 2015.

Concluding remarks

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

We look forward to a response to our feedback of this document.

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

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

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