WA Health - You Matter: engaging with consumers, carers, community and clinicians in health – Draft Framework

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AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

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ABOUT CARERS WA

Carers WA is the peak body representing the needs and interests of carers in Western Australia and is part of a national network of Carers Associations. Carers provide unpaid care and support to family members and friends who have disability, mental illness, a chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged. The person they care for may be a parent, partner, sibling, child, relative, friend or neighbour. Illness and disability are non-discriminatory and the caring role can be borne by any individual at any given time, regardless of socioeconomic status, age or location. Caring is a significant form of unpaid work in the community and is integral to the maintenance of our aged, disability, health, mental health, and palliative care systems. A report undertaken by Deloitte, Access Economics, 'The economic value of unpaid care in Australia in 2015', determined the replacement value of the care undertaken by carers in Australia to cost $60.3 billion per annum.

Some important facts about carers include:

- There are 2.86 million unpaid carers in Australia. More than 825,000 carers are primary carers.
- There are more than 320,000 family and friends in a caring role in Western Australia or approximately 1 in 8 in the community.
- Almost 80,000 carers live outside of the metropolitan area in Western Australia.
- Researchers suggest that only 4% of young carers between the ages of 15 to 25 are still in education, compared to 23 % of their peers.

ENQUIRIES

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Questionnaire Responses

1. **Email:** stephanie.fewster@carerswa.asn.au

2. **In what capacity are you providing your views for this survey?**

   Non-Government Organisation Employee

3. **What are your key sectors of interest when providing your views for this survey?**

☑ Aboriginal and/or Torres Strait Islander
☑ Culturally and Linguistically Diverse (CALD)
☑ Mental Health
☑ Disability
☑ Regional/Rural/Remote
☑ Youth
☑ Aged Care
☑ Homelessness

None, please specify your area of interest _**Carers**___

4. **Does your feedback represent an individual or group / organisational perspective?**
   An Organisation, Carers WA.

5. **What do you believe are the key strengths of the draft *You Matter: engaging with consumers, carers, community and clinicians in health*?**

Carers WA commend WA Health on the Draft Framework, "You Matter: engaging with consumers, carers, community and clinicians in health". It is a much more comprehensive document than that which was produced in 2007 and incorporates contemporary principles such as co-production and co-design and the different levels of engagement.

6. **What do you believe are the key weaknesses of the draft *You Matter: engaging with consumers, carers, community and clinicians in health*?**

Generally throughout the document

At times only consumers mentioned and at times consumers and carers. It has been seen by Carers WA that when only consumers have been mentioned in an Expression of Interest to join a committee within WA Health that carers do not identify with the term consumer and that at times there has been an oversight of including carers in service design, planning, delivery and evaluation. Consumers and carers have overlapping but significantly different input and needs when it comes to service delivery.

Recommendation 1 – Carers are listed separately to consumers throughout the document.

Page 4 and Page 17 – Vulnerable Groups

Carers are also listed as a vulnerable group in the Western Australian Health Promotion Strategic Framework 2012-16[1].

Recommendation 2 – Carers be listed under vulnerable groups within the Framework Summary and within the 'Vulnerable Groups' section.

Page 6 - Introduction

There is a comment about '*engagement at the individual level to support personal care is very important but not within the scope of the framework*'. Whilst we understand that the Framework does not include engagement at the individual level, engagement is not always about 'personal care' or treatment decisions. For example, engagement with the family/carer at an individual level may well provide important feedback about the service which may reflect their satisfaction as to how they were treated but also heeding this feedback may mitigate risks to the patient. Similarly individual interactions with community members or certain groups of people (e.g. ATSI) who accompany patients or who otherwise interact with the health service may have an impact on how they perceive the health service and their willingness to engage with the service.

Recommendation 3 - It would be worth mentioning, even though not in scope for this Framework what 'individual level' engagement takes place, impacts on the organisation and service delivery and how this is managed (e.g. via customer liaison officers).

Recommendation 4 – That there is some explanation of why the Framework does not include engagement at an individual level?

Page 9-10 – Who is engaging with WA Health Service Providers

The Top Tips for Engagement with Vulnerable groups provides valuable and practical information for engaging with each of these groups, Carers WA believe this would be valuable to be applied in this section also.

Similarly, Barriers to Engagement (under Clinicians) would be useful to apply under other groups that WA Health is engaging with

Recommendation 5 – That 'Top Tips for Engaging' tables be applied to each of the groups outlined, not just vulnerable groups and that Barriers to engagement also be applied to each of the groups in this section (not just clinicians)

Page 9 - Carers and support workers

It is not clear why support workers have been specifically singled out as a group for consideration under the Framework. They are not mentioned in the title nor are other community support services staff mentioned under the Framework. There are many people in the community who have extensive knowledge of patient's needs etc. who may actually have more in depth knowledge than support workers, who usually rotate through shifts or are transient in the length of time they provide care, e.g. long term community pharmacist or

[1] Australian Institute of Health and Welfare. Australia's health 2012. Australia's health no. 13. Cat. no. AUS 156. Canberra: AIHW, 2012. Available from: http://www.aihw.gov.au/publication-detail/?id=10737422172

the patient's GP. Support workers have many different roles, some are cleaning staff, and some provide personal care in the home or may provide support to people with disability, chronic illness who are aged or with mental health issues in supported accommodation. The reference provided which states '*Support workers are likely to know the changes that are required to improve patient care*' is part of a document about leadership and support workers being in a positon to influence change within the environment within which they work (i.e. in the community) not within the public health service.

Intermingling support workers with carers only serves to confuse the reader of the document as to the usually longstanding/ongoing role of a carer who is better placed to provide advocacy support for the patient and whose own needs should be considered under the Carers Recognition Act 2004. However carers as advocates are not mentioned. The draft Framework cites a statement regarding support workers and that they 'may' have a role in advocacy, yet within the same source document it states that '*In some instances , the key worker may <u>not</u> be the best person to be the patient's advocate*'

In cases where there is no family member or carer of the patient and the patient has a cognitive impairment then an appointed guardian would have a longer term view of the history of the patient and be able to provide ongoing feedback than an often transient or intermittent support worker.

Recommendation 6 – That support workers be removed from the document <u>or</u> if they are to be included that they be moved to the 'Community' section. If support workers are to be retained, then it is expanded upon as to what support worker engagement would provide to the health service and possibly list examples of other community supports that the patient may access that may also be desirable for WA health to engage with.

Recommendation 7 – A statement be included that carers usually have a long standing and/or ongoing relationship with the person they care for and therefore are uniquely placed to understand the implications of health service delivery on consumers, particularly where the consumer has cognitive impairment and where the carer is the advocate for the consumer. Additionally it should be noted that carers bring a different view of services to the consumer as to how the health service impacts on carers in their own right.

Recommendation 8 – That the Carers Recognition Act 2004 is referred to under 'Carers' section and the Carers Charter is correctly referenced.

<u>Page 12 – Engagement Levels</u>

The draft Framework states that individual engagement is not in scope for the Framework, yet states on page 12 that consumer, carer, community and clinician engagement with the WA health system can occur at an individual level.

Recommendation 9 – That there is some explanation of why the Framework does not include engagement at an individual level?

<u>Page 14 – Table 3 - Benefits of Engagement, Health Services</u>

One of the measures is reduced complaints and conflicts. It could be argued that many consumers and carers do not complain about health services due to the fear of retribution,

particularly those people from vulnerable populations[2]. Carers WA experience many carers who phone with complaints about health services but due to a combination of being time poor, stressed and fearing retribution via the care of the person they are complaining on behalf or attitude changes toward themselves in the past or in relation to speaking up, they are reluctant to do so. Health Services should welcome an increase in complaints which would indicate that consumers and carers feel comfortable in raising concerns and that the mechanisms to do so are accessible. A better measure may be that concerns, complaints and conflicts are resolved to the satisfaction of the people who are making them and that required local or systemic actions to prevent them recurring are put into place.

Recommendation 10 – Remove '*reduced complaints and conflicts'* and replace with, concerns, complaints or conflicts are resolved satisfactorily.

Page 17 -29 Remuneration and reimbursement of participation costs

The addressing of remuneration and reimbursement of participation costs is inconsistent throughout the document

- Is only addressed under vulnerable populations, not in the main sections of Consumer, Carers and Community.
- Does not appear to apply to some groups, e.g. homeless and ATSI in the document.
- Does not refer to an overall WA Health Policy in relation to reimbursement or remuneration.
- In some groups is referred to as remuneration and some reimbursement of participation costs. These are generally two different things with one being remuneration for time spent participating whereas reimbursement is generally for expenses incurred as part of participation e.g. parking expenses; it would be useful to have clarification of terms.

Recommendation 11 – that either a separate Policy be developed in relation to paid participation and the Framework refers to this or that part of the Framework is designated to setting appropriate remuneration and reimbursement guidelines as part of the Framework. A good example is the development of the Paid Participation Policy[3] by the Mental Health Commission which has a matrix outlining levels of engagement and appropriate remuneration and also addresses reimbursement of expenses. Now this is finalised it is being followed by the development of a Framework.

7. **If there are any weaknesses please provide suggestions as to how these could be addressed?**

   Please see recommendations as listed throughout section 6.

[2] Carney, T. (2016) Health Complaints and Regulatory Reform: Implications for Vulnerable Populations? *Journal of Law and Medicine, Vol. 23, No. 3, pp. 650-661, 2016* Sydney Law School Research Paper No. 16/27

[3] http://www.mentalhealth.wa.gov.au/Libraries/pdf_docs/Paid_Partnership_Policy_6.sflb.ashx

8. **Please provide any other comments concerning any aspect of the draft *You Matter: engaging with consumers, carers, community and clinicians in health*?**

Page 12 – Engagement Levels

The draft Framework states that individual engagement is not in scope for the Framework, yet states on page 12 that consumer, carer, community and clinician engagement with the WA health system can occur at an individual level. It is also stated on page 29, table 14 under engagement with homeless clients where it refers to effective interventions for complex problems.

Question 1. To clarify; are the individual interventions and engagement referred to above aim to assist a person/group to a point where they are then able to engage with a service or organisation with regards to service planning etc. rather than at the individual engagement (treatment) level?

Process – Page 15

As an example of demonstrating the engagement process in relation to this consultation, it would be recommended that people or organisations providing input are informed as to how they can get feedback as to why inputs were used or not and the reasons why

Question 2. How will WA Health provide feedback to those who have participated in the consultation as to how their input was used (or not) and the reasons why in the final document?

Page 38 – References

Reference # 16 – Should be Carers Association of WA or Carers WA.