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Re: Consultation on CHS Draft Consumer Handout Guideline

Thank you for the opportunity to provide feedback on the Canberra Health Services (CHS) Draft Consumer Handout Guideline (the Guideline).

The Health Care Consumers' Association (HCCA) is a health promotion agency and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on local health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA has had a long involvement in the CHS Consumer Handout Committee and has supported consumers representative for many years. Consumer handouts are important resources for consumers and there was considerable interest from our members in this review.



For this consultation we engaged with members of HCCA's Quality and Safety Consumer Reference Group, Health of Older People Consumer Reference Group, and our Access and Design Consumer Reference Group. . Many members have either received consumer handouts or been involved in their development or review, and have an interest in good communication for safer health care.

This submission covers the main issues we would like to raise. These are:

- The objective of the Guideline
- Structure and focus of the Guideline
- Developing consumer handouts
 - training
 - existing handouts
 - further information for consumers post-appointment

We have attached a copy of the Guideline with comments and track changes providing more detailed feedback.

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The Objective of the Guideline

Consumer handouts are a key health literacy resourceⁱ. It is important for health services to work in partnership with consumersⁱⁱ to ensure that written health information meets the needs of consumers, carers and families. The information contained in consumer handouts must be clear, understandable and easy to use.

As recognised in the Guideline, the Australian Commission on Safety and Quality in Health Care's (ACSQHC) National Safety and Quality Health Service (NSQHS) Standards (the Standards) require, across a range of Actions, the provision of information to consumersⁱⁱⁱ.

HCCA would like to see the Guideline articulate, beyond these requirements of meeting the Standards, that the ***provision of information to consumers about their health care is critical for ensuring that we understand care and treatment options, the decisions that can be made and any actions required.***

Structure and Focus of the Guideline

Consumer feedback we received on the Guideline was varied. One consumer commented:

I did another scan of this guideline after we discussed it today, and I am even more convinced that CHS really should scrap the guideline and start again.

The document does not advise the reader where they can access examples of user tested handouts or provide evidence based information about what a good handout looks like. It's not a 'how to write handout' guideline. In fact it just outlines how to get a handout signed off.

Consumers were concerned that the structure and objectives of the guideline focus too much on the process of getting a handout signed off and in circulation, rather than fulfilling the purpose of handouts – ie. to provide consumers with information that supports understanding of our health and health care.

We know that developing a good consumer handout is not an easy task. Given the purpose of handouts is to provide accessible information to consumers, the process of their development must be consumer-centred. There needs to be a partnership between consumers and health services, to ensure that consumer needs are understood. Staff require strong skills in readability and health literacy, to ensure that the information provided meets those needs. There also needs to be ongoing engagement and testing of resources to ensure their suitability over time as medical practice and the needs of consumers change.

The structure and focus of the Guideline needs to better represent the importance of ascertaining and meeting consumer needs, and then ensuring high quality consumer health information that supports the decision making and delivery of care.

Developing Consumer Handouts

Training

HCCA noted that Section 1 of the Guideline recommends that staff begin by completing the Capabiliti eLearning course *Writing Consumer Publications*. Consumers who commented on the Guideline were not across the content of this course, but hope that it helps staff to understand the health literacy and plain language requirements necessary for assessing existing handouts for suitability, as well as developing new ones.

Existing handouts

Wherever possible, HCCA suggests that CHS try to avoid creating handouts from scratch. We commend the idea in Section 3 of the Guideline of not 'reinventing the wheel' when it comes to consumers handouts. The Guideline indicates the need for staff to check that there are no existing CHS handouts, as well as to check the list of CHS 'approved external organisations'. Consumers questioned who and how these external organisations are 'approved', and how often this process takes place.

HCCA does not have access to this list, however consumers highlighted that it is important to recognise that there are many great consumer handouts that can often be easily accessed online. Handouts from reliable sources and well-resourced in development can be adapted to suit CHS. Other health services or consumer support groups are often more than willing to share their established resources. We would hope that the CHS 'approved external organisation' list includes a range of organisations around Australia, as well as internationally.

Adapting an existing handout can save considerable time and effort. Existing handouts may have already undergone levels of stakeholder and consumer review that is more difficult to achieve in a smaller jurisdiction like the ACT.

Existing consumer handouts that have been well-received by consumers may also have been translated into a range of different languages, or even plain English options for those with low literacy^{iv} We are interested to explore the use of Easy English for people with intellectual disabilities and people with cognitive impairments to support decision making. The translation of handouts can be costly and time consuming. It is fantastic to have translated resources available, and great if CHS can use or adapt existing resources.

More information about the benefits of adapting existing handouts could be incorporated into Section (3) of the Guideline to provide a stronger rationale around the importance of this step in the process.

Further information for consumers post-appointment

A gap in information for consumers can be after an appointment, when considering information that has been provided, including handouts. A consideration for the development of handouts should be contact details for where consumers can go or

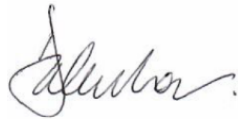
who they can contact if they need further information, without necessarily needing to make another appointment.

Final remarks

We thank you again for the opportunity to review this Guideline and to provide consumer input. This is an important guideline for CHS.

HCCA would be happy to further discuss our feedback, so please feel free to get in touch. We look forward to seeing how our comments shape the final document once the consultation is complete.

Yours sincerely



Darlene Cox
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ⁱ HCCA Position Statement on Health Literacy <https://www.hcca.org.au/wp-content/uploads/2018/09/Health-literacy-position-statement-FINAL.pdf>

ⁱⁱ For more on partnership or co-design, see HCCA Position Statement on Co-Design <https://www.hcca.org.au/wp-content/uploads/2020/06/HCCA-Co-design-position-statement-Final.pdf>

ⁱⁱⁱ NSQHS Standards (first edition): Standard 2: Partnering with Consumers - Tip Sheet 5: Preparing written information for consumers that is clear, understandable and easy to use <https://www.safetyandquality.gov.au/publications-and-resources/resource-library/nsqhs-standards-first-edition-standard-2-partnering-consumers-tip-sheet-5-preparing-written-information-consumers-clear-understandable-and-easy-use>

^{iv} The Canberra Health Literacy website could be a useful resource in this area <https://cbrhl.org.au/>