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HCCA Feedback on the Open Disclosure Resources

Background

The Health Care Consumers' Association (HCCA) of the ACT was formed over 30 years ago 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 consumer

HCCA is dedicated to the promotion of consumer-centred health care, which we believe can be successfully achieved through the application of five key principles:

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

Introduction

HCCA was asked to provide feedback on two open disclosure resources as part of the open disclosure training project being undertaken by the ACT Health Directorate. HCCA strongly supports the policy of open disclosure and believes it is an essential component of consumer-centred care and welcomes the opportunity to work with the Health Directorate to assist in ensuring its effective implementation. The first

resource is a brochure for consumers explaining the open disclosure policy and the steps involved, while the second is a questionnaire for consumers to fill out following an incident evaluating the open disclosure process as they experienced it.

The feedback included in this document has been developed in consultation with consumers, HCCA staff and members of the HCCA Executive Committee. In general, the focus is on ensuring that consumers are provided with adequate information following any incident that occurs during their health care and that they are treated with respect at all times.

Open Disclosure Brochure

Overall, HCCA is pleased with the open disclosure brochure as it presents information in a clear and accessible manner. However, there are a number of issues that need to be considered as well as some additional information that could be included for consumers.

HCCA would be interested to know in what stage of the process this resource will be distributed. We have assumed that it will be provided to consumers after the first face to face discussions have taken place and apologies have been made. Unless consumers have already been introduced to this policy, it may not be clear exactly what 'open disclosure' is referring to. As such, it may be worth including a brief definition of open disclosure on the front page, as well as inside the brochure, so that consumers can quickly recognise what the brochure is for. It would also be good to specify with whom the 'open discussion will occur, i.e. health professionals will engage in discussion with consumers involved with the incident.

In the first section of the brochure, the phrase 'an open disclosure meeting will be held' could be removed as this sounds excessively bureaucratic and does not provide any new information. It may be worth considering replacing this phrase with 'an open disclosure process will begin', as the brochure also includes reference to another resource explaining exactly what this process entails.

While HCCA strongly supports the process of conducting an investigation into all incidents that occur in health care, we believe it is equally important to share the results of these investigations with the consumers involved. This could be addressed in the brochure by adding a sixth point to the section outlining the benefits of open disclosure, stating that it will 'offer to provide you with further information about our investigations'.

It is also important to ensure that this policy is being applied equally to all consumers, especially those with culturally and linguistically diverse (CALD) backgrounds. Are there versions of this brochure available in different languages? In cases where language may act as a barrier to communication, it would be particularly difficult to implement the open disclosure policy effectively, so it is important to ensure that CALD individuals are able to access information about the

policy. Similarly, it would be good to get feedback from CALD individuals about their experiences with regard to open disclosure in order to identify any problem areas. HCCA would be interested to work with the Health Directorate on this.

It would also be good to provide consumers with contact details for a higher authority if they are unhappy with the response of the healthcare professionals involved following an incident, such as the Human Rights Commission. This is particularly important for incidents occurring in community service settings, where it might not be possible to contact a patient safety manager or equivalent.

Open Disclosure Questionnaire

HCCA is particularly pleased that an emphasis has been placed on obtaining consumer feedback on the efficacy of open disclosure. This is an excellent means of ensuring that open disclosure is being implemented consistently in all ACT Government health services and identifying areas that could be improved.

At the start of this questionnaire, more information could be given to the consumer about how the feedback they provide will be used to improve the open disclosure process as well as who they can contact should they have any further issues or questions they wish to raise. Consumers also need to be reassured that their confidentiality will be protected when they fill out the questionnaire, as they may be apprehensive about being critical towards their health care providers. Consumers often talk about their fear of retribution, making assurance that their feedback will not adversely impact on them critical.

HCCA also recommends that the item 'I was listened to' be either removed or revised, as the current wording comes across as being condescending. Following a serious incident, consumers would be expecting a lot more than to just be 'listened to', and in many cases it needs to be the health professionals who are doing the talking. One option might be to expand the item to something similar to 'the health professionals involved took into account all of my comments and concerns, and were understanding of my perspective'.

It may also be worth adding a few new items to the questionnaire. Firstly, an item similar to 'I am confident that the steps being taken to prevent this type of incident in the future will be effective' would be able to assess whether consumers feel as though enough is being done about the issue they have encountered. Another new item could relate to informing consumers as to the findings of investigations in accordance with our suggestions in the previous section.

As a final note, HCCA would like to refer the Health Directorate to the resource developed by the Royal Australian College of General Practitioners in close consultation with consumers entitled 'Regaining trust after an adverse event: a series of well timed conversations'. We believe that this resource outlines an

effective process for meeting consumer needs following an incident during health care. A link to this resource has been attached with this document.