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Professor Deborah Picone
Chief Executive Officer
Australian Commission on Safety and Quality in Health Care
GPO Box 5480
Sydney NSW 2001

Dear Professor Picone,

Re: Review of the Open Disclosure Standard

The Health Care Consumers' Association (HCCA) welcomes the opportunity to provide input into the Australian Commission on Safety and Quality in Health Care's (ACSQHC) review of the Open Disclosure Standard. Open Disclosure is an integral component of consumer centred care and is of great importance to our membership. HCCA participated in the initial consultations ten years ago in the development of the Open Disclosure Standard. We strongly support the work of the Commission in improving open disclosure in Australian health services and are very interested in providing continuing input to this process.

HCCA 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.

We have some comments relating to specific areas of the framework as well as some general comments that have been included at the end.

Use of the Word Disclosure

We consider the term 'disclosure' to be legalistic and give the perception that something has gone wrong. The Royal Australian College of General Practitioners (RACGP) uses the term 'open communication' and we are of the view that this is a more meaningful term. What we are talking about is open communication between consumers and clinicians about when things go wrong. This includes adverse events as well as sub-optimal outcomes. It is really important that 'open disclosure' is seen not only as information provision from the clinician to the consumer but a dialogue, a dynamic interchange of ideas and information. The term 'disclosure' suggests that it is a finite act and does not represent the process of listening and learning that takes place over time.

One of the barriers that we perceive to the implementation of the existing standard has been the heavy weighting given to medico-legal consequences. A focus on open communication rather than disclosure may help to reframe the conversation.

In reflecting of their experience of open disclosure, consumers have reported to us that they have been involved in fractious and highly emotional discussions and that health

professionals at times did not seem to be equipped to deal with it adequately. Consumers value a culture that supports clinicians during open disclosure.

Consumers want the clinicians involved in the incident to be involved in the disclosure process. They want to face them; they want to see their humility and humanity.

1.2 - Principles for Open disclosure

We support the principles included in the draft framework. Principle five, Supporting Clinicians, is a very important principle. Unless clinicians are supported and trained, they will not be able to be effective contributors to any process involving open communication around adverse events.

2.3.2 – No-Harm Incidents

This is an area where we think reporting can be improved and low level disclosure needs to take place. Examples of these incidents include an arm falling from the operating table when the patient is anaesthetised or the wrong IV bag hung. While these are incidents that may not have significant adverse effect on the patient, nonetheless, harm has occurred and there needs to be more consistency about disclosing this rather than simply dismissing it as a no-harm incident.

3.1 - Informed Consent

We are very concerned that informed consent has been identified as being out of scope for the framework. You cannot have open disclosure without informed consent. Open communication between consumers and their clinicians begins with informed consent. Without informed consent, how do consumers and our families know when things have gone wrong? Informed consent is critical to our capacity to identify adverse events and sub-optimal outcomes.

The AMC Code of Conduct for Good Medical Practice for Doctors in Australia states that:

“Informed consent is a person’s voluntary decision about medical care that is made with knowledge and understanding of the benefits and risks involved.” (p.5)

We would encourage the Commission to use work of the AMC on informed consent. We want to make sure that what is included in the draft framework is consistent with the key messages that are used in the training and registration of health professionals. For example, the Medical Board of Australia has endorsed the Code of Conduct developed by the AMC and clearly sets out their expectations of what doctors need to do. Given the sensitivity and importance of open disclosure, there must be consistency. We note that open disclosure is included in the National Standards at 1.16.

In section 2.6 of the draft framework, the Commission identifies the importance pre-incident care in determining the success of open disclosure. We think that this relates to informed consent and is another demonstration of why informed consent is not out of scope for this framework.

3.5 – Educational Institutions

The framework needs to be more specific in referring to allied health professionals, nurses, and midwives. Open disclosure needs to be an integral part of all undergraduate training in health care as well as the advanced training in specialities. We would encourage the Commission to map where open disclosure appears in curricula.

4.4 – Particular Patient Circumstances

We see that there are two particular groups who are deserving of special consideration. These are vulnerable people living with disadvantage and consumers and their families from culturally and linguistically diverse (CALD) backgrounds. We would encourage the Commission to work with consumer organisations to enhance their understanding of the needs of these groups. We also see that there is potential for the Commission to build relationships with community organisations in developing a response to the needs of these people. For example, the Australian Council of Social Services (ACOSS) has significant insight into the experiences of vulnerable people and the Federation of Ethnic Community Councils of Australia (FECCA) could provide valuable insight into issues for people from CALD backgrounds.

13 – Achieving Closure

The word 'closure' has negative connotations for consumers as it implies a linear process with a beginning and a clear end. Consumers we have spoken to who have experienced adverse events did not talk about closure, as there are ongoing consequences for them. This section needs to be clearer about its intended purpose. We think the title 'reaching shared agreement' is more appropriate because it is about reaching shared agreement on the process and the outcomes.

General Comments

There are a few general points that we would also like you to consider in refining the framework:

- As it stands, the draft framework is focused on the acute setting and needs to be broadened to be more inclusive of health services provided in other settings.
- There needs to be consistency in the use of terms 'patient', 'consumer', 'carer' and 'family'
- Many hospitals run during business hours, yet we know that things can go wrong out of these hours. We would like consideration to be given to encouraging services to think about how they will be able to respond when adverse events happen on weekends or public holidays. This is especially related to section 10.3.
- Consumers value the reporting culture in the public hospital systems and would very much like this extended to the private sector and community based services.
- We would like to see consumer reporting of adverse events used to escalate the process to investigation.
- The framework needs to be promulgated widely and we would like to see a range of guides developed for different audiences. A busy junior doctor in a rural hospital may

have different information needs to a senior allied health professional working in private practice, and indeed different again to information needs of consumers.

- We want the framework to have teeth. We don't just want an aspirational statement of intent. Open disclosure is very important to consumers.

We are very happy to discuss our submission further.

Darlene Cox,
Executive Director