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Re: Review of Draft Consent and Treatment Policy

The Health Care Consumers' Association (HCCA) welcomes the opportunity to provide consumer input to Canberra Health Services' (CHS) Draft Consent and Treatment Policy. HCCA is a member-based organisation and to review this guideline we undertook a targeted consultation with consumers from our Health Policy Advisory Committee, and Quality and Safety Consumer Reference Group. We also received feedback from our organisational member, the AIDS Action Council of the ACT.

HCCA commends CHS on working towards having policies and procedures in place to help ensure that consent processes are done well across the organisation. However, it is disappointing that consumer input provided by HCCA to date does not appear to be reflected in the draft policy. HCCA's Health Policy Advisory Committee met to specifically discuss consent in September 2019 and our consumer representative, Fiona Tito Wheatland, provided a comprehensive paper to the Consent Working Group following this meeting. The paper gave numerous case studies and outlined some of the key issues around how consent processes have fallen down or worked well in the experiences of consumers and carers. It also stressed that, for consumers, the act of providing truly informed consent, requires that the clinician or clinical services provide good information to consumers throughout their whole patient journey. All consent processes must reflect principles and actions which embody shared decision making with the patient/consumer or their substitute decision-maker.

Context for consumer consent in health care

Australian common law about the standard of care about information-giving by health professionals as part of seeking consent from a patient requires that the information health professional give fulfils two standards. The first is an objective standard, where information on a proposed treatment, its risks, benefits and other alternatives, that would be required by a reasonable patient must be provided. The second is a more subjective standard which requires that where a particular patient asks for information, then the health professional must address their specific information needs. These standards both require the clinician or service seeking consent to

have processes which give a patient the information required "as they are", thus taking into account their individual communication needs eg for a translator, the opportunity to ask questions and seek clarification, the availability of support for their decision-making such as through the presence of someone they trust like an advocate or friend. Sometimes consent will be required several times over one period of treatment eg if a new medication is introduced, or actions are required that are different than those previously discussed with a patient or their family.

In addition to the legal principles requiring the provision of reasonable or requested information to patients as core parts of any consent process, Australia's National Safety and Quality Health Service (NSQHS) Standards outline a number of key actions under Standard 2 – Partnering with Consumers. These actions are centred around the concepts of:

- health care rights and informed consent (Action 2.3-2.5)
- sharing decision and planning care (Action 2.6-2.7)

These actions are consistent with the Australian Charter of Healthcare Rights (2nd ed.).

We suggest that the CHS Policy on Consent could better reflect this framework, , recognising that consent is not limited to a legal understanding, or to health service risk management, but that it is ***an integral part of the practice of shared decision making in health care***.

Key feedback from HCCA

In light of consent as an integral part of the practice of shared decision making, we would like to highlight the following key points of feedback about consent:

- Consent is a continuum across the patient journey – there is not necessarily one point for consent in an episode of care after which consent no longer needs to be considered.
- It is not just doctors, but other staff that can, and should, play a role in consent.
- Clear processes must be in place for ensuring consent where substitute decision makers are involved. In these cases, the clinicians should seek to engage the person with impaired decision-making ability as much as they can through processes of supported decision-making to find out their wishes and to understand and, as far as possible, to address any concerns they have.
- Consumers need to be supported by staff in shared decision making processes, to ensure we have sufficient information to make an informed decision about our treatment or care. For example, this could involve the shared use of Choosing Wisely Australia's "5 questions to ask". Processes should ensure that health professionals encourage people to ask these questions and are prepared to engage in a conversation about these questions with a patient and their family or advocate before "seeking consent".

- Some consumers will need additional support to make decisions around consent – this could include a family member, advocate or peer support person.
- The principles of trauma informed care are also important to help people feel safe while being informed and making a decision. This may require staff training.
- A process for communicating this policy is missing from the document – it is not clear how the policy will be communicated to staff or consumers. Will there be staff training in consent? How will consumers be able to understand the concepts and processes of consent used in CHS?

Specific comments

In our consultation with consumers in reviewing this policy, a number of specific issues were raised.

1. Title – consumer feedback suggested that the policy title did not reflect their vision of the integral role of consent in health care.
2. Length of this policy document – many consumers commented that 35 pages seemed too long. . There was confusion about parts of the policy that seemed procedural. We suggest considering a shorter policy document with more specific advice in attachments or as part of an accompanying procedure, to make it easier for staff to find the information they need in a timely manner.
3. Definition of consent (p3) as both “valid” and “informed” needs further explanation. For example, to be “valid”, consent needs to be informed, explicit, specific, willing and can be withdrawn at any time (suggested that this would be consistent with the definition of consent that is being taught in schools).
4. One specific issue that has been brought to our attention lately relates to the often extensive delays between a first consultation to get on a service or providers waiting list and the time of intervention. There have been examples where the patient’s condition and clinical needs have changed dramatically, and this has not been noticed until the patient is under anaesthetic. At the point of getting on the waiting list, one treatment was agreed to, and then by the time of the intervention, another is provided on the basis of clinical necessity without seeking consent of the person, their family members or substitute decision-maker. Another consumer described giving informed consent in a doctor’s rooms some months before, and when the person arrived in the pre-operative space after their pre-medication, being told by the doctor that he was going to do a different procedure that he had learned since their discussion and requiring her to sign a different consent form.
5. Responsibility for obtaining consent (p8-9) – there is concern from consumers about the implications for junior doctors where other health professionals might refuse to undertake the consent process (p9). This seems contrary to a supportive culture and unfair that senior staff could choose to delegate their responsibilities around consent to junior staff.

6. The issue of patients being clearly able to withdraw consent to a treatment, if they are finding it too onerous was also raised by some members, particularly in the context of death and dying. One consumer mentioned that when her husband sought to withdraw his consent to treatment, that considerable pressure was placed on him to "continue to fight" and the doctor refuse to listen to the family who were supporting their husband and father in his decision. In the context of a later complaint by the family, the intransigence of the doctor was recognised as inappropriate by the senior hospital management but it was seen as "his way". The concern felt by the family about their loved one not being listened to and being put through significant pain and suffering at the end of his life not only led to a formal health complaint but they have suffered a great loss of trust in the health system because of their experience. They were not able to find out who or where to go to address the matter as it unfolded, and they strongly believe that a process should available for family members concerned about a provider ignoring the wishes of their loved one, who is seeking to withdraw his or her consent.
7. It is important that the system recognises that a consumer may make different choices than a doctor or other health professional. There were also examples, where people were concerned that if they disagreed with a doctor, that this would be seen as evidence that they were not legally competent, and decisions would be handed over to someone else. This can be a real concern for someone with a life-limiting or complex condition, involving consent at many points. It is also of concern when an unexpected outcome occurs and further treatment to address the consequences of that outcome may be required.
8. Is there a Territory-Wide approach to interpreter services and communicating to those without English as a first language? We hear cases of consumers from non-English speaking backgrounds who did not feel they were able to provide valid consent for medical and dental procedures, but where they were also not offered an interpreter to assist with communication and provision of information.
9. Furthermore, consumers have told us that staff are sometimes unaware about when interpreter services are needed, and how these services can be contacted. Consumers suggested that at the very least, access to online programs such as Google translate could provide help for staff and consumers to access help for communicating in day-to-day care in an admission, for example.
10. Section 9 (Culturally and linguistically diverse people and those with special needs) rightly recognises that communication in other languages or in different ways can be essential to facilitate understanding for provision of information and decision making towards informed consent. A consumer

noted that this can also be relevant to Section 8 – Aboriginal and Torres Strait Islander Peoples.

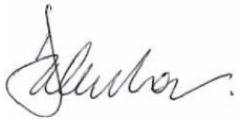
11. There was also a suggestion that Section 9 Culturally and linguistically diverse people and those with special needs) should recognise 3 distinct groups (in order to have sensitivity to the needs of each of these groups when they use health services):
    - cultural and linguistic diversity
    - special needs (eg. accessibility, physical/mental impairment)
    - sex, sexuality and gender diversity
12. In relation to communicating in such a way as to facilitate understanding, it is important to recognise that individual consumers will have different information needs and preferences. For example, some consumers will prefer online information over paper, some may require a visual aid such as a model of a joint or body part, some need simple language, some need interpreter services or information presented in their own language (other than English).
13. Section 10 – Consumer Handouts - needs to mention the possibility of accessing information in other languages.
14. Evaluation measures (p24) for this policy are insufficient, as RiskMan is likely to only pick up a very limited range of incidents, if any, relating to consent. What measures will be used to assess the effectiveness of the policy, or ascertain whether further information is required to meet consumer and staff needs around consent?

We have also attached a copy of the policy document with tracked changes, highlighting some minor edits and other additional feedback.

Next steps

We thank you for the opportunity to provide feedback to this consultation process. HCCA's Health Policy Advisory Committee remains interested in meeting with the CHS Consent Working Group for further discussion about the integral role of consent across the patient journey. We would much appreciate such an opportunity to help ensure that the final policy reflects and supports a consumer-centred approach to consent across CHS.

Yours sincerely



Darlene Cox
Executive Director
11 March 2020