



Ms Josephine Smith
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Dear Ms Smith

Operational Policy: Consumer Privacy

Thank you for the opportunity to comment on Canberra Health Services' Consumer Privacy Policy. Fiona Tito-Wheatland, Kathryn Briant and I also appreciated the opportunity to discuss our concerns with you and Jacqui Clissold, on 20 May 2019. Since we discussed our legal concerns at the meeting and you also have a copy of Fiona's notes, we have not included this additional information in our feedback.

As you may know Health Care Consumers' Association (HCCA) is a member-based organisation. For this submission we received some targeted input from consumers involved in quality and safety issues and members of our Health Policy Advisory Committee.

Yours sincerely

A handwritten signature in black ink that reads "K Dwan".

Dr Kathryn Dwan
Manager, Policy and Research, HCCA

**HCCA Feedback on the
Canberra Health Services:
Operational Policy on Consumer Privacy**

Submitted 30 May 2019

Contact: Dr Kathryn Dwan
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General Feedback

As part of HCCA's 2017 research into quality and safety, we explored what good quality health care looks like to carers and consumers. Our research found that respect, information and communication are all important to providing good quality care. These features of care align well with the Picker Principles for Person Centred Care.¹ They are also important factors to consider in Canberra Health Services policies and processes for consumer consent.

Following on from this research, in 2018, HCCA developed a Position Statement on Consumer-Centred Care. Consumer-centred care is a foundational principle in all our work, and we promote this approach to health service providers, within government and across the ACT community. In part, consumer-centred care

- is responsive to someone's unique circumstances, and
- tells consumers, carers and families what they can expect from healthcare providers and the health system.²

As such, consent policies and processes form part of delivering consumer-centred care.

HCCA appreciates this opportunity to provide feedback and to partner with Canberra Health Services in ensuring that processes for consent that are clear, health literate, and meet the needs of consumers and of the organisation. The CHS Operational Policy and related consumer information on consumer privacy and consent relates directly to the Australian Charter of Healthcare Rights, in particular the rights of Communication, Participation and Privacy³. We also recognise that consent is particularly important as it forms part of the National Safety and Quality Health Service Standards. Standard 2 – Partnering with Consumers, 2.3-2.5 outlines consent as a part of partnering with patients in their own care⁴.

Specific Feedback

Operational Policy – Consumer Privacy

Several consumers commented that the Operational Policy was very dense with text. Feedback suggested the following improvements:

- The "Purpose" section of the document doesn't appear until page 4 – it would be useful to have this upfront in the document, as the first heading. Likewise, we suggest that the scope of the document also belongs upfront. The scope of the document should make clear that this is one of a group of three documents, each with its own purpose – the other two being (1) information privacy policy, and (2) clinical records management policy.
- It is necessary for the initial pages of text to be so dense? We suggest breaking up the text with headings to better guide the reader to its contents.

Additionally, some of the information could be moved to an appendix. For instance, the privacy principles could be added as an attachment or link, and a much shorter summary appear in the document.

- It would be good to ensure consistent terminology for consumers. In particular, we would like to see correct use of the possessive singular (consumer's) and the plural possessive (consumers').
- Policy documents, such as this operational policy, use to include a section on "Monitoring and Evaluation". We believe that the monitoring and evaluation of this policy is imperative. Furthermore, it will require both dedicated time and a process to measure what is happening and what outcomes are achieved. A good monitoring and evaluation process could integrate with current audit processes and tell us whether the policy is effective. It might also help to identify any changes or adjustments that are needed to improve the implementation of these processes.
- There is no mention in the Operational Policy of the importance of consent as a part of National Safety and Quality Health Service (NSQHS) Standards. We suggest that Standard 2 – Partnering with Consumers (specifically section 2.3-2.5) provides a good context, in addition to the legal framework, as to why this Operational Policy must be implemented across CHS. The NSQHS Standards should be included in the Background text of the document as well as in the "Related Policies, Procedures, Guidelines and Legislation".
- The "Alerts" section, currently on p.3-4, includes some vital and important information for staff. We suggest putting this upfront in the policy document, perhaps even straight after the "Purpose". In its current position, the alerts section feels too hidden in the dense text of the document.
- Consideration must be given to people who have literacy challenges – the policy needs to impress on staff the need to provide clarification, assistance to translation and/or interpreting services, as well as verbal information, before seeking consent from the consumer or carer.
- One consumer commented that they felt the policy should include a statement which indicates that Canberra Health Care staff should not engage in conversation in the public space (i.e. non-treating area) where the identity of the persons discussed, or issues relating to those persons, may become common knowledge.

Consumer Information Sheet

As part of reviewing this consumer information sheet, we looked at other similar information sheets. We have found two examples from other jurisdictions which provide good models. Both are easy to read, use shorter sentences, and are set out in a question and answer format.

- http://healthtranslations.vic.gov.au/bhcv2/bhcht.nsf/PresentDetail?Open&s=Cconsumer_privacy_information_brochure

- <https://metrosouth.health.qld.gov.au/sites/default/files/content/informed-consent-english.pdf>

To improve accessibility and inclusivity, we suggest that the national interpreting symbol (see below) should appear at the top of the first page, rather than in such small font at the end of the document. We also recommend positioning the National Translating and Interpreting Service's number (13 14 50) directly under the logo. The combination alerts consumers to the help available and makes it easy for them to access it.

To assist CHS in improving the consumer information sheet, we have put together an example based on the draft consent form provided but in a similar format to the information brochure provided by Health Translations Victoria (see **Attachment A**).

Consumer Consent Form

HCCA has reworked the content and format of the consent form to ensure that consumers can understand it (**Attachment B**). Once again, we have been informed by the work of Health Translations Victoria and Metro South Health in Queensland. Their material is clear and easy to understand for consumers. The form from Health Translations Victoria has proved simple enough to translate into other languages.

- [http://healthtranslations.vic.gov.au/bhcv2/bhcht.nsf/PresentDetail?Open&s=Consent to share information](http://healthtranslations.vic.gov.au/bhcv2/bhcht.nsf/PresentDetail?Open&s=Consent_to_share_information)

We have some core suggestions, which apply not only this form but all consumer forms:

- Font size – We recommend a minimum of 12pt. We also encourage you to produce the form in 14pt for people whose eyesight is declining or is impaired in some way.⁵
- Space for written text – We recommend more space be provided for people when they are required to write anything.
- Sub-headings – We recommend that the form is separated into sections that clearly identify the focus of the consent statements. For example
 - Sharing information within Canberra Health Services
 - Sharing information with your GP and other health professionals
 - Sharing information with your family members, carers and friends
 - Understanding how to withdraw consent
 - GRANTING CONSENT – SIGNATURES
 - Withdrawing consent
 - WITHDRAWING CONSENT – SIGNATURES
- Check boxes – These makes the consumer's wishes abundantly clear to anyone reading the form.

In addition, we feel that if the legislation covering the topic is included in the information sheet, appropriately referenced, and where the information sheet is an integral part of the consent process, there is no need to repeat it again in the consent form.

Unresolved issues associated with the consent form

- The consumer needs a [copy of the signed form](#). Without it, they may not recall what was agreed or even that they can change their consent.
- The consent form may need to include the [contact details](#) of the individual who has given consent, because it may not be the patient.
- The consent form states

I understand that [my personal information will be shared with the Canberra Health Service staff members](#) providing me care while I am admitted at a Canberra Health Service facility.

HCCA is concerned that this wording does not alert the consumer to the existence of [patient journey boards](#) that may be stationed in public spaces. Nor does it mention the [electronic white boards](#) that eventually will be stationed beside every bed.

- The consent form may need to specify [what information](#) is to be shared with [which health professionals](#). For instance, if the consumer has signed a Benzodiazepine Voluntary Undertaking this may be relevant to their care in hospital and to the care provided by their GP but not to other health professionals (e.g. physiotherapist, podiatrist).
- Similarly, the consent form may need to specify [what information](#) is to be shared with [which family members, carers and friends](#). This may be particularly relevant when it comes to Indigenous and individuals from culturally and linguistically diverse backgrounds.
- The consent form will need to be able to address the situation where [anonymity](#) is important for the safety of a patient or is otherwise the consumer's choice. Presumably there are existing processes and perhaps policies that address this. However, the form needs to be designed in such a way to cope with the possibility. One option is to establish at the top of the consent form whether this is an issue, and if so, a different form or process may be needed.
- The option to use a [pseudonym](#) may need to be included on the relevant consent form. If information is simply not displayed on the patient journey boards, then this effectively identifies the bed of a vulnerable person. This could put already vulnerable people at significant risk of harm.

Concluding remarks

HCCA looks forward to seeing how our feedback is incorporated into the final operational policy on Consumer Privacy and the related consumer information sheet and consent form.

Please do not hesitate to contact us if you wish to clarify any aspect of our feedback or have further discussion on the issues raised.

¹ The Picker Institute developed eight principles of Person Centred Care:

<http://pickerinstitute.org/about/picker-principles/>

² HCCA Position Statement on Consumer-Centred Care <https://www.hcca.org.au/wp-content/uploads/2018/09/Consumer-Centred-Care-Position-Statement-FINAL-.pdf>

³ Australian Charter of Healthcare Rights <https://www.safetyandquality.gov.au/national-priorities/charter-of-healthcare-rights/>

⁴ NSQHS standards, pp14-17 <https://www.safetyandquality.gov.au/wp-content/uploads/2017/12/National-Safety-and-Quality-Health-Service-Standards-second-edition.pdf>

⁵ Supporting information on text size and readability for consumers can be found here:

<https://discoveryeye.org/print-and-web-design-for-older-adults/>

<https://www.fonts.com/content/learning/fyti/situational-typography/designing-for-seniors>