Shakira Spiller
Director, Innovation & Improvement
Quality, Safety, Innovation & Improvement
Canberra Health Services (CHS)

shakira.spiller@act.gov.au

chs.qsii@act.gov.au

**Submission on draft CHS Consent to Healthcare Treatment Guideline**

Thank you for the opportunity to provide feedback on the Consent to Healthcare Treatment Guideline ("the Guideline").

Informed consent sits alongside evidence-based clinical practice at the core of all healthcare treatment. Given this importance we suggest that rather than a 'Guideline' the Consent to Healthcare Treatment be a Standard. This will align the document more clearly with the National Safety and Quality Health Service Standards and Australian Charter on Healthcare Rights. Clearer connection between the local and national Standards and the Charter will improve the authority of the local Standard.

As noted in our submission the draft Guideline:

- is written in a way of how informed consent is applied to rather than worked with consumers in partnership;
- needs to frame consent as an ongoing dynamic process rather than an "end point";
- has inconsistencies in terms of language ("should", "will", "must) and application to staff (e.g. sometimes mentioning "all staff", "clinicians" and even "students"); and
- has internal inconsistencies in its application of informed consent (for example, indicating that assessing for capacity to consent is not required in an emergency).

We note the short timeframe provided for input on this substantial Guideline. We anticipate our consumer representatives will provide additional feedback and we will onforward this when received. We also note in our submission that we have previously provided feedback on informed consent within CHS in 2016, 2019 and 2020 and strongly encourage incorporation of this prior feedback.

Yours sincerely

Jessica Lamb
Senior Policy Officer
18 December 2023

**Health Care Consumers' Association**
100 Maitland Street, HACKETT ACT 2602 Phone:02 6230 7800
ABN: 59 698 548 902 Email: adminofficer@hcca.org.au
hcca.org.au | HCCA.ACT | @HealthCanberra

**SUBMISSION**

# Draft Consent to Healthcare Treatment Guideline

## Canberra Health Services

December 2023

## About HCCA

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 involves consumers through:

- consumer representation and consumer and community consultations;
- training in health rights and navigating the health system;
- community forums and information sessions about health services; and
- research into consumer experience of human services.

HCCA is a Health Promotion Charity registered with the Australian Charities and Not-for-Profits Commission.

## HCCA's approach to this submission

HCCA is a consumer and community organisation. We draw on the views and experiences of our membership and networks to advocate for consumers.

In preparing our response to this Inquiry we have drawn on the knowledge, experiences and concerns of our members as they relate to the draft Guideline. We also draw upon our previous submissions on ACT Health and CHS consent policy and procedures provided in 2016[1], 2019[2] and 2020[3].

## 1. General comments

Position consumers as active decision-makers on informed consent

In our previous research, we found that consumers perceive that consent is done to not with them.

Whilst acknowledging the Guideline is directed at CHS staff, there is an opportunity throughout the Guideline to reinforce that the consumer is the decision-maker. The framing of consumers as the active decision-making would be enhanced by the inclusion of a section on consumer rights and 'clinician' responsibilities.

We have previously suggested reference to the Picker Principles of Person Centred Care[4] particularly:

- Involvement in decisions and respect for preferences;
- Fact access to reliable healthcare advice;
- Clear information, communication and support for self-care; and
- Involvement and support for family and carers.

Positioning the Guideline within these guiding principles positions consumers' needs as a central and integral part of the informed consent process.

Consumers rights and 'clinician' responsibilities

The document would benefit from being framed around consumer rights to actively give, decline and/or withdraw their informed consent. 'Clinician' responsibilities can then be positioned within consumers' rights to informed consent through a partnered and shared decision-making relationship.

This can be done by referencing the Australian Charter of Healthcare Rights (specifically the rights to Partnership and Information) and the Partnering with Consumers Standard within the National Safety and Quality Health Service Standard (particularly Partnering with Consumers in Their Own Care and Health Literacy).[5]

Consent as a dynamic, ongoing and variable process across the continuum of care, not an "end point"

We are concerned with the language and framing of consent as an "end point" in the Background section and throughout the document and note our previous feedback that "consent is continuum across the patient journey – there is not necessarily one point in an episode of care after which consent no longer needs to be considered"[6]

Consent is a *dynamic* process that occurs between the consumer (including their friends, family and carers), the clinician(s) (and other healthcare staff) and the condition, including the treatments being considered. It is also an *ongoing* process that needs to be continuously monitored for changes, including the consumer's condition (and any additional information that may need to be communicated to the consumer) and their ongoing capacity to consent.

Most importantly, consent can be withdrawn at any time so it is never an "end point."

Communication of consent between treating clinicians and teams

We note the absence of guidance around the communication of a consumer's consent, and any limitations, among and between treating clinicians and teams. We understand the Guideline refers to the documentation of consent, whether given orally or in writing, but there is a need to reinforce with clinicians that they communicate a consumer's consent to others as well as noting in the patient file.

Inconsistent/incorrect application of assessment of capacity to consent

The application of the need to assess for the capacity to give informed consent is inconsistent (incorrectly) applied.

For example, in the Consent to Healthcare Treatment Adult Flowchart presented in Appendix B if the answer to the first box question "Is this an emergency" is "Yes" then the next action is

> "Proceed **without** consent" (emphasis added)

Which negates all the material in the Guideline that requires clinicians/healthcare staff to **assess capacity** or the availability of substitute decision-makers. For example, in Section 11 it is stated "While the key requirements for valid consent outlined in Section 1 **remain applicable at all times**…". That is, it should not be assumed that because a consumer has been triaged as an emergency that their capacity to give consent is absent or that the need for consent can be ignored.

Guideline or Standard?

As noted above, making this a Standard rather than a Guideline emphasises the importance of information consent in the delivery of healthcare. Strengthening to links with the National Safety and Quality Health Service Standards ("the National Standards" and the Australian Charter of Healthcare Rights ("the Charter") by placing these and quoting from them at the beginning of the document will also improve its authority. We encouraged the reference to the National Safety and Quality Health Service Standards and Australian Charter of Healthcare Rights in our 2019 submission[7]. In the submission we also noted that the "Purpose" (in the current document "Key Objective" (*sic*) is not at the very beginning of the document, comes after "Background" material and is not in the Table of Contents.

Who does the Guideline apply to?

At various points reference is made to clinicians, all staff, CHS staff and students. While a definition is provided at the end of the document it does not cover all the ways in which staff have been referred to in the document.

Absence of a trauma informed approach to informed consent

There is no reference to the principles and practices of trauma informed care and how these relate to informed consent.

Physical and digital documentation of consent

The Guideline refers to the need for documented consent forms to be placed on the consumer's record. Consumers have told us they would also like a copy of the consent form so they can refer to it later, possibly when they are better placed to absorb the information fully.

Consumer representatives asked how the Guideline applies to Digital Health Records and if consent is being obtained through it and, if so, how consent is being handled in that environment.

We would welcome the opportunity to review any CHS approved consent forms (physical or digital) in use and whether translated versions are available.

Consumers with additional access and inclusion needs including those living with disabilities

We previously suggested the separation out of the needs of three distinct groups[8]:

- people from multicultural backgrounds;
- people with accessibility needs including disabilities and impairments, including those with lower literacy levels; and
- people of diverse sex, sexualities and genders.

This section needs to include reference to the use of braille, large format, Easy Read and Auslan to enable informed consent. Again, Health Literacy is an important component of the National Standards and the Charter. Further information on the importance of health literacy for health services is on our website[9]

We support the provision of material in culturally appropriate ways as identified in the section for Aboriginal and Torres Strait Islander people and a similar approach can be taken with the groups identified above.

Consumer representatives thought that information on these groups should be provided earlier in the document. They also asked if the need for an interpreter/translated information is on the admissions form. They suggested a statement that Telephone Interpreter Service (TIS) translators should be involved as early as possible in the consent process, including when consent is raised by Junior Medical Officers working to consultants. They also suggested that the TIS logo and number along with contact details for the Aboriginal Liaison Officer be placed at the beginning of the document for easy reference.

Privacy

The document only includes two references to 'privacy'. In our previous feedback, we noted that a consumers spoke to the importance of discussions on informed consent being conduct as privately as possible. They spoke of the need to keep identifying information, either of the person or the treatment, protected. We think reference to the

CHS Information Privacy Policy and the National Privacy Principles would be useful here.

Responsibility for implementation, communication and evaluation of the Guideline

While it is stated that the Executive has responsibility to "Ensure the principles and requirements for consent are applied, achieved, sustained, monitored and evaluated" it is unclear how they will do this, how it will be measured and to whom they will report.

An Evaluation section is provided but it only proposes a goal that "staff are aware of" the Guideline, not that they act in accordance with it. The Evaluation section does not contain any measures, indicators or targets, baseline measure of these nor how frequently they are to be collected.

No indication is given who is responsible for carrying out the evaluations and who they will report them to.

Consistency of language

The draft Guideline variously uses "should", "will" and "must" throughout. Our preference is for "must" that the Guideline is applied across all situations and is not merely a 'guide' to be considered (and potentially ignored).

## 2. Detailed comments on proposed amendment

Please see the annotated document attached which should be read in conjunction with this submission.

[1] https://www.hcca.org.au/wp-content/uploads/2022/06/FINAL-HCCA-Feedback-on-the-Consent-and-Treatment-Policy-February-2016.pdf
[2] https://www.hcca.org.au/wp-content/uploads/2022/06/20190530-HCCA-Submission-ACT-Health-Consumer-Consent.pdf
[3] https://www.hcca.org.au/wp-content/uploads/2022/06/HCCA-Final-Submission-Consent-and-Treatment-Policy-2020.pdf
[4] https://picker.org/who-we-are/the-picker-principles-of-person-centred-care/
[5] https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard
[6] https://www.hcca.org.au/wp-content/uploads/2022/06/HCCA-Final-Submission-Consent-and-Treatment-Policy-2020.pdf p.2
[7] https://www.hcca.org.au/wp-content/uploads/2022/06/20190530-HCCA-Submission-ACT-Health-Consumer-Consent.pdf
[8] https://www.hcca.org.au/wp-content/uploads/2022/06/HCCA-Final-Submission-Consent-and-Treatment-Policy-2020.pdf
[9] https://www.hcca.org.au/for-health-providers/health-literacy-health-services/