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HCCA Submission on the Draft Consent to Treatment Policy and Standard Operating Procedures

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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 consumers

HCCA welcomes the opportunity to respond to the *Draft Consent to Treatment Policy* and *Standard Operating Procedures*. Our comments are informed by consultation with our membership.

Overall, HCCA is pleased with the ACT Health Directorate's continued understanding of the importance of informed consent practices in ensuring consumer-centred care, as well as safe and high quality health service delivery.

However, from a consumer perspective there are ways in which the Policy, Standard Operating Procedures (SOPs) can be improved. Both the Policy and its associated SOPs use ambiguous language, such as "could" and "should", implying option rather than necessity, which is not merely a question of semantics when such significant issues are under consideration. Also, the Policy and its SOPs comprise a large number of pages, and several consumers questioned the accessibility of such a format to frontline staff. If these documents are truly intended to provide guidance for staff, rather than act as an insurance policy for the Health Directorate in times of crisis, they need to be streamlined.

In addition, several areas and issues mentioned require clarification and expansion, including:

- Assessment of capacity;
- The use of consent forms and ensuring that the consumer is informed;
- Informed financial consent; and
- Refusal of information.

The driving force behind the concept of informed consent is ensuring the autonomy of the consumer, that is, our fundamental right to control our lives and actions through choice. As a result of the increasing ability of consumers to educate themselves around their own health issues, it is of vital importance, both morally and legally for doctors to obtain informed consent before performing medical/surgical procedures that have the potential to cause harm to the consumer. However, the term "informed consent" is used so frequently within this context that it is somewhat diminished in its ability to provide clarity. To borrow a phrase from former justice Michael Kirby, "[a] phrase begins life as a literary expression; its felicity leads to its lazy repetition; and repetition soon establishes it as a legal formula, and undiscriminatingly used to express different sometimes contradictory ideas."[1] As such, in order for any policies and Standard Operating Procedures (SOPs) to be meaningful to the frontline staff who access them, the key concepts under consideration must be made clear, and other issues within these procedural documents outlined above, must be addressed in order to ensure that the regime of informed consent is truly effective.

Assessment of capacity

A key factor in obtaining informed consent from a consumer is determining whether the particular consumer has the ability to understand the treatment options and thus provide truly informed consent. This concept is addressed in both the Policy and SOPs, but there is little guidance regarding how this decision is actually arrived at. The Consent to Treatment Policy says that the decision regarding capacity is arrived at after a "clinical assessment", however it is not clear how or by whom such a process is conducted.[2] The issue of assessment capacity is of particular concern to mental health consumers, where stigma around mental illness can impact on the fair assessment of capacity. As such, the process by which capacity is assessed must be both accurate and transparent.

Assessing the capacity of someone to consent in an emergency situation also required clarification. The law allows for medical treatment to be conducted without consent in an emergency situation and where the consumer lacks the ability to consent through injury or illness. This lack of capacity caveat needs to be made clear. It needs to be emphasised that unless consumers are unconscious or otherwise severely incapacitated, they are still potentially able to understand the treatment process and are still able to give consent, depending on the nature of the emergency.

The acknowledgement of the autonomy of the patient in the Capacity and Substitute Decision Maker SOPs is most welcome. It must be recognised that even if the consumer makes an alternative decision to the one suggested by the medical professional, or refuses treatment altogether, this does not negate the consumer's consent capacity.

The issue of consent as it regards minors is also potentially problematic. The arbitrary adult age of 18 says little about a person's abilities of comprehension, and

[1] M.D. Kirby, "Informed consent: what does it mean?", *Journal of Medical Ethics*, 9:2 (1983) 70.
[2] "Draft Consent to Treatment Policy", *ACT Health Directorate* (2012) 4.

the Policy and its SOPs address this. The Children or Minors SOPs allows that a consumer can consent to medical treatment if they are "mature enough" to be able to understand the treatment process and its risks.[3] However, there is little guidance on what this actually means in practice, and how an assessment of capacity should be arrived at in this instance. "Mature enough" is an ambiguous phrase which requires expansion if it is to be useful guidance to frontline medical staff making these kind of decisions. Additionally, it needs to be made clear whether minors are required to provide written consent, given that they are under the age of majority.

The use of consent forms and ensuring that the consumer is informed

The Policy and its SOPs provide for the use of written consent forms in certain circumstances. HCCA understands that it is not practical for consent forms to be required for the administration of every basic procedure, such as the dispensing of medication or taking blood, where verbal consent will suffice. However, HCCA believes that consent forms should be more widespread than they are currently, and should be employed in order to ensure informed consent for more procedures which, though simple, may carry risks. In connection to this, it is worrying that consultations performed by students require only verbal consent, rather than written. It would be appropriate for students to be required to obtain written consent, not only for the consumer's benefit, but also to familiarise them with the practice. In addition, the fact that VMOs are allowed to use their own consent forms is potentially problematic, as there is no way of ensuring uniformity of the information provided by these health care professionals. Consent forms within the public sector of the ACT should be standardised. The Consent to Treatment SOPs allows that the responsibility of obtaining informed consent and a signature on a form can be delegated to another health professional, who is able to perform this task "within their scope of practice".[4] In order to increase clarity, and expansion of the definition of who can obtain informed consent from a consumer should be provided.

While HCCA advocates for more widespread use of standardised consent forms, this is in addition to other forms of informing consumers, not as a replacement. The Consent to Treatment SOPs allow for the provision of pre-prepared written or audio-visual resources to consumers. HCCA argues that these kinds of resources should be provided to consumers routinely, as both a means of ensuring the quality of information, and as a complement to other sources of information.

In addition, consent forms and pre-prepared resources should not seek to replace face-to-face discussion between consumers and their health care providers. While the ability of consumers to adequately understand the information provided in a consent form is increasing, there can be issues with lack of recall and comprehension of consent forms, which are often written in a jargonistic and legalistic manner. As such, there is no replacement for actual discussion, conducted in an open and non-coercive manner, with the clinician understanding the unequal power relationships at play, and encouraging questions in order to facilitate comprehension. Clinicians have an obligation, which should be reflected in the Policy and SOPs, to explain procedures in simple language, but without

[3] "Draft Consent to Treatment: Children or Minors Standard Operating Procedures", *ACT Health Directorate* (2012) 1.
[4] "Draft Consent to Treatment Standard Operating Procedures", *ACT Health Directorate* (2012) 2.

condescension, in order to facilitate greater consumer comprehension. This process not only benefits the consumer, but also allows the health professional to take note of what information has been provided, allowing the clinician to easily facilitate the process of providing key information.

The Consent to Treatment SOPs indicate that "sufficient time" must be given for consumers to process the information provided and arrive at an informed decision.[5] "Sufficient time" is a vague term, and it must be emphasised that consumers should not feel rushed into any decision by clinical staff. Consumers should be given the opportunity to contact staff when they feel they have arrived at an appropriate decision.

Another key factor which can impact on a consumer's ability to consent, and one which is largely absent from the Consent to Treatment Policy and its SOPs (a small section in the Consent to Treatment SOPs notwithstanding), is the status of the consumer as culturally and linguistically diverse (CALD). The linguistic ability of consumers needs to be reflected as a factor which can impact on their capacity to consent. Language barriers can be a huge issue for CALD consumers and need to be addressed from the outset, by employing trained interpreters or an interpreter service such as the national Translating and Interpreting Service. Staff need to be made aware of these services, so that they are able to access them when required. In addition, CALD consumers may come from cultures where questioning figures of authority, such as medical staff, is considered inappropriate. Therefore, attention needs to be paid to creating a safe and encouraging environment, and building a relationship between consumer and clinician, so that CALD consumers feel comfortable seeking clarification about treatment options.

Informed financial consent

Informed financial consent is becoming more of an issue for consumers in the ACT, and in other states, as reported by HCCA's sister organisations across Australia. As some hospitals and health services attempt to reduce costs by shifting them to the consumer, issues arise with appropriate consent processes. The Consent to Treatment SOPs provide a demonstration list of key points that should be communicated to the consumers, including the time and cost involved, and any out of pocket expenses. HCCA would like to emphasise the importance of providing this financial information to consumers, as it can impact on their decision making process, and more importantly, is their right to know the cost burden they will have to bear from the outset of any treatment.

Refusal of information

HCCA acknowledges that some consumers will decline to be informed about their treatment options, and are happy to agree with their treating clinician's suggestions. However, the refusal to provide information to consumers, which is allowed under law where it would be "damaging to a consumer's physical or mental health" is problematic.[6] Withholding information from consumers is an incredibly paternalistic

[5] "Draft Consent to Treatment Standard Operating Procedures", 6.
[6] "Draft Consent to Treatment Standard Operating Procedures", 6.

approach, especially when the consumers have not personally indicated a refusal of information. There needs to be more guidance in the Consent to Treatment SOPs around when, and *if,* this course of action is appropriate. For example, there needs to be a clearer process for determining why and how the information might cause harm to the patient, and an indication of this course of action as very extreme. If information is being withheld from consumers without their knowledge, it is impossible for them to fully understand the treatment and its risks, and thus to provide informed consent, invalidating the whole process.

References

M.D. Kirby, “Informed consent: what does it mean?”. *Journal of Medical Ethics* 9:2 (1983) 69-75.

“Draft Consent to Treatment Policy”. *ACT Health Directorate* (2012).

“Draft Consent to Treatment: Children or Minors Standard Operating Procedures”. *ACT Health Directorate* (2012).

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