Sub #7.

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Health Consumers Queensland ... your voice in health

Submission to Queensland Parliament Health and Disabilities Committee:

Queensland Law Reform Commission Recommendations on Guardianship Laws Inquiry

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1. Health Consumers Queensland

Health Consumer Queensland's (HCQ) Terms of Reference and Mission are to support the voices of Queensland consumers to achieve better health outcomes. HCQ does this by contributing to the continued development and reform of health systems and services in Queensland by providing the Minister for Health with information and advice from a consumer perspective, and by supporting and promoting consumer engagement and advocacy. HCQ's aim is to strengthen the consumer (patient) perspective in health policy development and system reform and improvement.

HCQ comprises a 12-member Ministerial Consumer Advisory Committee (Committee) and a Secretariat. The Committee is comprised of a mix of health consumers from a broad range of health populations and social groupings.

In line with HCQ's priority areas - quality and safety; equitable access and targeted responses; and participation and engagement - and its recent body of work in relation to Advance Care Planning and Advance Health Directives HCQ provides the following submission to the Health and Disabilities Committee's *Queensland Law Reform Commission Recommendations on Guardianship Laws Inquiry* and welcomes the opportunity to provide comment.

2. Scope of this submission

HCQ's response has been informed by feedback from its 12-member Ministerial Consumer Advisory Committee, HCQ's statewide Consumer Network of 235 individual and organisational members and recent work undertaken by HCQ around
Advance Care Planning and Advance Health Directives in Queensland.

Within the context of state and national health reform HCQ has been undertaking a project to explore consumer views in relation to advance care planning and Advance Health Directives (AHDs) to achieve better outcomes for Queenslanders. HCQ initiated this work in response to ongoing feedback from our Consumer Network in relation to the complexity of advance care planning and AHDs, and the need for reform at state and national levels.
Consumer feedback from HCQ's work to date indicates there are four strong themes which relatee to the improvements and reforms health consumers consider necessary to better protect and recognise their rights, interests and autonomy in healthcare decision-making, and to meet their needs around advance care planning and AHDs. These are:

1. Reform of legislation relating to AHDs
2. Improved mechanisms to record, store and access AHDs
3. Improved information and support for consumers
4. Improved support for health practitioners to undertake advance care planning

HCQ's committee has considered six draft options for improvement and reform of advance care planning and AHDs, arising from the four key themes. Some of these relate to key issues explored in the Inquiry Issues Paper and will be discussed later in this response. Consumer input and feedback received from the project was used to inform HCQ's October 2010

response to the Australian Health Ministers' Advisory Council's *Draft National Framework for Advance Care Directives* (**Attachment A**).

This submission provides both general and specific comments relevant to advance care planning, advance health directives, end-of-life decision-making and the Inquiry's terms of reference. It will not address all aspects of the Inquiry's terms of reference and questions in the Inquiry Issues Paper; rather it will focus on those issues upon which HCQ has received feedback and/or commented on in its Draft National Framework submission.

3. General Comments

HCQ commends the Queensland Parliament for initiating this consultation and engaging with consumers and key stakeholders around core recommendations proposed by the Queensland Law Reform Commission (QLRC) in its September 2010 *Review of Queensland's Guardianship Laws final report.* HCQ welcomes the Inquiry's focus on advance health directives, withholding and withdrawing of life sustaining measures and objection by an adult to health care.

Overall, consumers support a consumer-centred approach to advance care planning and AHDs, and consider AHDs a valuable tool for providing directions about the care and treatment they wish to receive in the event they lose capacity to make decisions for themselves. However, to enable effective advance care planning, consumers strongly emphasise the need for their right to autonomy and self-determination in healthcare decision making to be respected and adhered to in practice by health professionals and service providers.

While there is widespread consumer support of AHDs as a mechanism for providing directions about healthcare and treatment, some consumers have indicted to HCQ they prefer not to have an AHD. As such, HCQ considers the making of an AHD should be voluntary, in accordance with consumers' right to autonomy and self-determination in healthcare.

4. Specific Comments

HCQ provides the following specific comments in response to the Inquiry Terms of Reference.

ADVANCE HEALTH DIRECTIVES

When an Advance Health Directive can not operate (QLRC recommendation 9(3)(b))

In consulting with consumers in relation to the Inquiry Issues Paper, HCQ received diverse views about whether the *Powers of Attorney Act 1998* (Qld) should be amended to clearly state that an AHD can not operate if it is uncertain or if circumstances have changed to the extent that had the patient known of the changed circumstances they would think the AHD was inappropriate.

In its response to the Australian Health Ministers Advisory Council's consultation on the Draft National Framework for Advance Care Directives (**Attachment** A) HCQ provided consumer feedback around the need for any nationally consistent legislation governing AHDs to include a requirement for regular review of a Advance Care Directive (ACD) (i.e. every two years, or upon significant changes to an individual's health circumstances), or for ACDs to be time-limited.[1] Time limitation of ACDs and the requirement for regular review would also potentially overcome issues relating to uninformed decision-making through:

- enabling patients to record their most recent views about treatment/care;
- be informed about current treatment options before making a ACD; and
- providing opportunities for further consultation with a health professional to obtain information and advice.

Accordingly, HCQ suggests the Committee give consideration to introducing provisions to time limit AHDs, or require regular review of AHDs as an alternative to QLRC Recommendation 9(3)(b).

HCQ also notes that in its *Review of Queensland's Guardianship Laws* report the QLRC recommended AHD forms should include questions which draw the principal's attention to whether a direction refusing healthcare treatment is intended to operate in unforeseen circumstances (ie. where the need for healthcare does not arise from an existing condition or the natural progression of a condition).[2] HCQ supports this approach and considers it could be useful in overcoming the difficulties and uncertainty which arises where it is unclear whether a direction is intended to operate in unforeseen circumstances.

Ensuring that health providers are aware of Advance Health Directives and Enduring Powers of Attorney (QLRC recommendation 9.11)

HCQ supports the QLRC's Recommendation 9.11 which obliges healthcare facilities (including hospitals, residential aged care facilities and residential disability care facilities) to take appropriate steps to record and store AHDs on patients' health records to ensure improved health professional access to and awareness of AHDs.

HCQ supports the use of personally controlled electronic health records (PCEHR) as an appropriate mechanism to record, store and access AHDs and considers healthcare providers should be required by law to take appropriate steps to record and store AHDs on patients' health records. HCQ believes such an obligation would improve health providers' access to and awareness of AHDs and enduring powers of attorney.

[1] Health Consumers Queensland, *Submission to Australian Health Ministers' Advisory Council's Draft National Framework for Advance Care Directives* (October 2010) 7.
[2] Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws Discussion Report Volume 2* (2010) 111.

Recording and storing AHDs through PCEHR provides the following benefits to consumers and health practitioners and service delivery:

- Instantaneous access to AHDs by health professionals;
- Expedient administration of treatment, particularly in emergency situations;
- Respect for patient autonomy through ensuring the patient's wishes in relation to medical treatment and care are known and followed;
- Access to AHDs in states and territories other than the patient's primary place of residence, and by health providers/services throughout the nation;
- It would replace potentially unreliable and inconsistent current and proposed mechanisms to record the existence of an AHD (such as wallet cards, fridge magnets, hard copy files and filing systems, etc), which are often problematic to locate or consult in an emergency situation, through introducing a streamlined, nationally consistent system.

As PCEHR are to be controlled by and readily accessible to individual consumers, recording and storing AHDs through PCEHR would better enable consumers to access their own information about their AHD; would improve self-management and informed decision-making, and would be of use when consumers review their AHD and/or consider making changes to an existing AHD.

HCQ received consistent feedback throughout its Advance Care Planning and Advance Health Directives project that stronger mechanisms are required to ensure health professionals, providers and services are aware of the existence of a patient's AHD, and are able to readily access it. HCQ considers health services (including health clinics, general practices, hospitals, residential aged care facilities and residential disability care facilities) should be obligated to make enquiries of all patients receiving care or services from them whether the patient has an AHD, and should ensure a copy of the AHD or a note about the AHD's existence is on the patient's file. Where the patient has impaired capacity, their substitute decision-maker should be asked about the existence of an AHD. The patient's treating health professional or treatment team should also be aware of the existence of the AHD and have a copy of it.

Protection of health providers for non-compliance with an advance health directive (QLRC recommendation 9.18)

HCQ considers the protection for a health provider who does not follow a direction in an AHD because s/he believes it is inconsistent with good medical practice should be omitted.

Consumers have expressed concerns about this protection as they consider it fundamentally impedes their right to autonomy in healthcare decision-making. As noted by legal commentators:

> *... One of the critical functions of AHDs is that they allow adults to make decisions with which treating health professionals (and others) may disagree. An excuse that permits noncompliance with a refusal of treatment based on notions of good medical practice defeats that function and should not be recognised.*[3]

Accordingly, as the law currently stands, a consumer *'cannot be confident that his or her advance directive will be followed if it is not considered good medical practice for treatment to be withheld or withdrawn'*.[4]

HCQ notes that the notion of good medical practice 'has no equivalent at common law'[5] and that no other Australian jurisdictions protect a health professional in this way.[6]

HCQ also notes that the Australian *Code of Good Medical Practice* (which prescribes the professional and ethical conduct of all doctors practising medicine in Australia) requires doctors, in caring for patients towards the end-of-life, to:

- Manage a patient's symptoms and concerns in a manner consistent with their values and wishes;
- Accept that patients have the right to refuse medical treatment;
- Understand the limits of medicine in prolonging life and recognising when efforts to prolong life may not benefit the patient; and
- Understand they do not have a duty to prolong life at all costs.[7]

Doctors are therefore professionally and ethically obligated to respect patients' right to autonomy and wishes around healthcare, treatment and withdrawal or withholding of treatment.

HCQ believes that consumers' wishes, values and beliefs (including cultural and religious beliefs) and any direction in an AHD reflecting these should be respected and honoured, consistent with the fundamental common law right to autonomy and self-determination in healthcare decision-making. HCQ considers that these rights should prevail, and that health practitioners should not depart from a valid, unambiguous direction in an AHD. It is further considered that the risk that health practitioners may disregard a direction, including a direction to withhold or withdraw a life-sustaining measure, in a valid AHD should be negated.

Accordingly, HCQ supports the QLRC's proposed amendments to section 103(1) of the *Powers of Attorney Act 1998* (Qld) (recommendation 9.18)[8] to uphold consumers' rights to

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[3] Willmott, Lindy and White, Benjamin P. and Howard, Michelle T, 'Refusing advance refusals: advance Directives and life-sustaining medical treatment' (2006) *Melbourne University Law Review*, 30(1). pp. 211-243, 242.

[4] Ibid.

[5] Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws Report Volume 2* (2010) 79

[6] Ibid, 84.

[7] Australian Medical Council Ltd, *Good Medical Practice: A Code of Conduct for Doctors in Australia* (2009) 3.12.

[8] HCQ notes that the QLRC's proposed amendments to section 103(1) are premised on section 36 of the *Powers of Attorney Act 1998* (Qld) being amended as per its Recommendation 9-3: Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws Report Volume 2* (2010) Recommendation 9.3 (p.109).

autonomy and self-determination in healthcare decision-making and to ensure consistency with the common law and other Australian jurisdictions.

COMMON LAW RIGHT TO CONSENT OR REFUSE TREATMENT

HCQ supports amendment of the guardianship legislation to ensure that common law rights to consent to or refuse health care (provided they are clear, unambiguous and valid) are not affected by the legislation, as recommended by the QLRC in recommendations 9.26; 9.27 and 9.28.

HCQ considers such an approach would provide necessary clarification around consumers' fundamental common law right to consent to or refuse care and treatment, consistent with autonomy and self-determination in health care decision-making. It would better ensure consumers' wishes around future healthcare and treatment, in the event of loss of decision-making capacity, are respected where a formalised statutory advance health directive is absent.

DECISIONS TO WITHHOLD OR WITHDRAW A LIFE-SUSTAINING MEASURE

Direction in advance health directives to withhold or withdraw a life-sustaining measure (QLRC recommendation 11.3)

HCQ supports omission of the current limitations in section 36(2) of the *Powers of Attorney Act 1998* (Qld) which restrict when a direction in an AHD to withhold or withdraw a life-sustaining measure can operate, in accordance with the QLRC's recommendation 11.3.

Consumers have expressed that the current limitations are contrary to the common law and the position in other Australian jurisdictions where there are no limitations on the circumstances in which an adult's refusal of a life-sustaining measure will be effective.[9] It also negates consumers' inherent right to autonomy and self-determination in health care decision-making. HCQ therefore considers the current restrictions on the circumstances in which a direction to withhold or withdraw life-sustaining treatment may operate unjustifiable, and supports the omission of section 36(2) of the Powers *of Attorney Act 1998* (Qld).[10]

In this regard, HCQ also supports removal of the exclusion of blood transfusion from the definition of a life-sustaining measure, in accordance with the QLRC's recommendation 11.2.

Withholding or withdrawing artificial nutrition or hydration (QLRC recommendation 11.3)

HCQ considers the limitation in section 36(2)(b) of the *Powers of Attorney Act 1998* (Qld) contrary to consumer's rights to autonomy and self-determination in healthcare decision-

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[9] *Airedale NHS Trust v Bland* [1993] AC 789, 857 per Lord Keith; *Re B* [2002] 2 All ER 449; *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229.

[10] Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws Report Volume 2* (2010) Recommendation 11-3.

making and does not support a direction to withhold or withdraw artificial nutrition or hydration being differentiated from other life-sustaining measures. HCQ therefore supports QLRC recommendation 11.3 to omit the limitations which currently apply to such a direction.

In circumstances where an adult with impaired capacity has directed artificial hydration or nutrition be withheld or withdrawn, HCQ emphasises the importance of good communication between health professionals and family members to ensure all relevant information is provided to families/substitute decision-makers, including the risk and benefits of withdrawing or withholding artificial hydration or nutrition.

Consent to withholding or withdrawing a life-sustaining measure by a substitute decision-maker (QLRC recommendations 11.4, 11.5 and 11.6)

HCQ considers that in circumstances where health professionals and substitute decision-makers have conflicting views on whether a life-sustaining measure should be withheld or withdrawn, alternative dispute resolution mechanisms such as mediation should be utilised prior to referral of the dispute to the Adult Guardian, particularly where the substitute decision-maker's view is based on wishes clearly expressed by the adult when the adult had capacity. Where mediation is unsuccessful, the matter should be referred to the Adult Guardian as a last resort.

Such an approach would provide improved opportunities for resolution of the conflict without statutory involvement, and may better facilitate decision-making by the parties who best know the adult's views, values and wishes; and their medical history, diagnosis and prognosis.

If mechanisms for mediation or conciliation were introduced, HCQ emphasises the importance of such processes being undertaken expediently to avoid prolonging any pain, distress or suffering experienced by the adult.

HCQ also recommends resources be directed to establishing appropriate alternative dispute resolution mechanisms, as well as to information provision to better support substitute decision-makers and families throughout the decision-making process to enable them to make well-informed, appropriate decisions which reflect the adult's wishes.

Consent to withhold or withdraw a life-sustaining measure that is medically futile (QLRC recommendations 11.7 and 11.8)

HCQ considers consumers have a right to be fully informed about their health treatment and options in a clear and open way, and notes the inherent common law right of consumers to consent to or refuse medical treatment, even where it may result in their death. Where a consumer has impaired decision-making capacity, the consumer's substitute decision-maker should be consulted and their consent obtained about any proposed investigations, care and treatment.

As such, even where health care is considered by health practitioners to be futile, HCQ believes consent should be required to both withhold a life-sustaining measure, and to withdraw a life sustaining measure which has been commenced.

Consumers have expressed concern that the 'futility' of the treatment is based on the health practitioner's opinion, and that the most appropriate approach, in line with consumers' right to self-determination in healthcare decision-making, is to consider futility from the consumer's point of view, taking into account what his/her values, wishes, and beliefs would have been if s/he had capacity. As noted in the QLRC's report:

> *The problem with making determinations of futility purely the prerogative of the physician is that assessments of outcomes, benefits and burdens incorporate and reflect the values, concerns and perspective of the individual making the assessment.*[11]

Substitute decision-makers must be provided with all relevant information regarding treatment options and prognosis in order to make a fully-informed decision, regardless of whether the treatment option/s discussed may not prolong life or are considered futile.

Some consumers have also raised that they perceive there is a tendency for some health professionals to 'overtreat', and as a result consumers may receive futile treatment they do not want. This also supports the need for futile treatment to, at the very least, be raised and discussed with substitute decision-makers to enable fully informed decisions which accord with the consumer's values, beliefs and wishes to be made.

Consumers have also provided feedback that discussing futile treatment options with substitute decision-makers ensures improved accountability and transparency around health professionals' practice.

With respect to emergency situations, HCQ considers all reasonable steps must be taken to obtain consent from substitute decision-makers, including where the treatment is futile.

Potential criminal responsibility for withholding or withdrawing a life-sustaining measure (QLRC recommendations 11.15 and 11.16)

HCQ supports amending the Criminal Code to remove any doubt that a health provider who withholds or withdraws a life-sustaining measure in accordance with the guardianship legislation will not be criminally responsible.
Consumers have identified to HCQ that some health professionals may be reluctant to follow an AHD which results in a patient's death due to the risk they may be held criminally responsible and prosecuted. Where this occurs, the consumer's fundamental right to refuse medical treatment is breached.

Due to the inconsistencies which currently exist between Queensland's *Criminal Code*, the *Guardianship and Administration Act 2000* (Qld) and the *Powers of Attorney Act 1998* (Qld) regarding criminal responsibility of health practitioners for the withholding or withdrawal of

[11] Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws Report Volume 2* (2010) 227.

life-sustaining treatment, there is uncertainty and doubt for health professionals about their obligations and responsibilities, and liability under the criminal law.[12]

In Western Australia, this issue was overcome through introducing a legislative amendment to the *Criminal Code* (WA) such that it now provides that a person will not be criminally responsible for not administering or ceasing to administer treatment (in good faith and with reasonable care and skill) where it is reasonable to do so.[13] The patient's state at the time and the circumstances of the case must be taken into account.[14]

HCQ agrees with and supports the QLRC's recommendations to amend Queensland's legislation to better protect health professionals from criminal responsibility for acting in accordance with a valid AHD. Amendments of this nature would ensure existing inconsistencies are addressed, and clarification of the current position at law. It would also provide better protection for health professionals from criminal responsibility and prosecution for complying with valid AHDs in which a patient/consumer refuses life-sustaining treatment, and would reduce reluctance to follow such a direction.

As noted by the QLRC, it would also ensure that health professionals will be protected from liability not only where they withdraw or withhold life-sustaining treatment where an adult has impaired capacity, but also where an adult still has capacity and gives a direction to that effect.[15]

OBJECTION BY AN ADULT TO HEALTHCARE

HCQ supports QLRC recommendation 12.6 and considers:

- The authority to provide urgent healthcare to an adult without consent to meet an imminent risk to life or health should be clarified so that it can only be provided without consent to an adult with impaired capacity if it was not reasonably practicable to obtain consent from a relevant person under the guardianship laws.

- It should not be possible to provide healthcare without consent to meet an imminent risk to life or health if the health provider knows the adult has previously objected when they had capacity, whether in an AHD or otherwise.

HCQ considers all reasonable steps should be taken to consult with and obtain the consent of an adult's substitute decision-maker to health care, even where there is an imminent risk to life or death to the adult, to ensure the healthcare accords to the greatest extent possible with the values, wishes and beliefs of the adult had they had capacity. This would better ensure consumers are not administered emergency treatment which they do not want.

[12] Ben White, Lindy Willmott and John Allen, 'Withholding and withdrawing life-sustaining treatment: criminal responsibility for established medical practice?' (2010) 17 *Journal of Law and Medicine* 849; Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws*, WP 68 (2009) 328 – 331; Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws Report Volume 2* (2010) 260-277, particularly 275. While, Willmott and Allen support a similar approach: Ben White, Lindy Willmott and John Allen, 'Withholding and withdrawing life-sustaining treatment: criminal responsibility for established medical practice?' (2010) 17 *Journal of Law and Medicine* 849, 865

[13] See *Acts Amendment (Consent to Medical Treatment) Act 2008* (WA) and *Criminal Code* (WA) s259(2).

[14] *Criminal Code* (WA) s259(2).

[15] Ibid, 276.

Further, consumers may have previously discussed their wishes around healthcare or treatment in an emergency with family members – in such situations consultation with substitute decision-makers would enable both clarification of the adult's wishes and consent to be obtained.

With respect to provision of healthcare without consent when the health provider knows the adult has previously objected, such an approach is not only inconsistent with a patient's right to refuse consent to treatment, but may constitute an assault on the adult.

OTHER QLRC RECOMMENDATIONS

Registration of enduring powers of attorney (QLRC recommendation 16.5)

HCQ agrees that it is appropriate that registration of enduring powers of attorney is not required.

During its consultation around advance care planning and AHDs, HCQ received consumer feedback about the need for improved mechanisms to record, store and access AHDs, and to ensure health professionals are aware of their existence. While some consumers provided feedback about the need for the introduction of a national register for AHDs, HCQ considers that registers are expensive to implement, operate and maintain, time-consuming for health professionals to access and can be ineffective, particularly where registration is not compulsory. These comments are also relevant to consideration of registration of enduring powers of attorney and for these reasons HCQ does not support their registration or the establishment of a register.

As noted above, HCQ supports the use of personally controlled electronic health records through eHealth to record, store and access AHDs and considers eHealth the most appropriate mechanism for recording, storing and accessing enduring powers of attorney.

Charging of fees by the Adult Guardian (QLRC recommendation 29.1)

HCQ supports the QLRC's recommendation to retain the status quo so that no fee is charged for guardianship services. HCQ considers the introduction of fees would not be conducive to access and equity and would serve only to financially disadvantage already vulnerable consumers with impaired decision-making capacity.

5. Additional Comments

HCQ's committee has considered draft options for improvement and reform around advance care planning and AHDs to achieve better outcomes for consumers which are detailed below for the Health and Disabilities Committee's information. . These will also be included in an issues paper which HCQ is currently finalising with its stakeholders and Government.

- **Reform of legislation relating to AHD, including national legislation and mutual recognition:** HCQ supports national legislation for AHDs and harmonisation of laws to ensure clarity, consistency and mutual recognition of AHDs through the Australian States and Territories.

- **Improved information and support for consumers**: There is a need for user-friendly information and education strategies, programs and initiatives to be established and implemented statewide to promote and enhance community awareness and understanding of AHDs. Programs and initiatives should also be established to enable consumers to obtain support, advice and assistance in relation to advance care planning and AHDs.

  Further work needs to be undertaken to identify, consider and address the issues for rural and regional consumers, culturally and linguistically diverse consumers and Indigenous consumers around advance care planning and AHDs. A national, simplified, user friendly AHD form, and nationally consistent policies and practices to support consumers with fluctuating decision-making capacity are also required.

- **Improved support for health practitioners around AHDs:** HCQ supports either the introduction of a Medicare Benefits Schedule (MBS) item number for advance care planning or including advance care planning in the extended consultation MBS Item number to better enable health professionals to undertake care planning and completion of AHDs with consumers.

HCQ urges the Queensland Government should also work with the State, Territory and Commonwealth Governments, health professional bodies and tertiary institutions to implement nationally consistent undergraduate and postgraduate education and training, and continuing professional development for health professionals around advance care planning and end-of-life issues.

6. Conclusion

HCQ welcomes this opportunity to provide consumer perspectives to the Health and Disabilities Committee in relation to the Queensland Law Reform Commission Recommendations to Guardianship Laws Inquiry. HCQ strongly supports reforms in this area to improve legislation, policies, procedures and practice around advance health directives and end-of-life decision-making for Queensland health consumers.

HCQ supports ongoing engagement of health consumers and stakeholders around guardianship laws to ensure the needs and perspectives of consumers, as users of healthcare services, are considered.