



His Excellency the Honourable
Paul de Jersey AC, Governor of
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Health and Other Legislation Amendment Bill 2016

Submission from Palliative Care Queensland

This submission is made to the Legal Affairs and Community Safety Committee; Queensland Parliament on behalf of Palliative Care Queensland (PCQ). PCQ is an independent not-for-profit peak body representing the interests and aspirations of all who share the ideal of quality care at the end of life for all. PCQ is a membership organisation supporting the needs of palliative care providers, consumers and their families and those with and interest in palliative care in Queensland.

This submission refers to the proposed amendments to the *Hospital and Health Boards Act 2011*, notably the facilitation to enable general practitioners to have access to the Queensland Health Database, *The Viewer* and enable more efficient disclosure of confidential information for research purposes. PCQ's position on this is:

- 1. In principle, PCQ fully supports the proposed amendments to the *Hospital and Health Boards Act 2011* in relation to enabling General Practitioners to access *The Viewer*, with appropriate safeguards (as outlined by Minister Dick in the First Reading Speech) are in place.**

PCQ endorses the needs based approach to end of life care service development, as articulated by Palliative Care Australia (PCA 2005) in a plan for providing equitable access to end of life care while promoting effective and ethical use of resources.¹ Furthermore, Palliative Care Outcomes Collaboration (PCOC) data indicates that 34% of specialist palliative care provision in Queensland occurs in the community,² and the majority of this care involves primary care providers, principally General Practitioners.

In order to meet the needs of patients whose end of life care needs may be more complex General Practitioners need to manage the care of their patients with a terminal (or life limiting) condition, and to work in consultation with specialist palliative care providers. In order to achieve this, and to ensure the best quality care for patients, General Practitioners need access to accurate and timely health information (specifically discharge plans, test results, records of visits to emergency departments etc.) for the patients they care for.

Currently, General Practitioners (and other primary care providers) rely on patients and families to provide such information, via hard copy documentation; and outdated methods of communication from tertiary providers, such as faxing. This is problematic and can lead to delays in treatment and care. PCQ believes that providing access to *The Viewer*, will provide accurate and timelier access to information, and will result in improved communication and care.

Palliative care in Queensland occurs in all settings of care, including hospitals (public and private), community and residential aged care. The care of patients in the last twelve months of life is often shared across several settings. For example a patient with a diagnosis of advanced cancer may be

receiving palliative chemotherapy in a private hospital setting, have specialist palliative care outpatient appointments at a public hospital setting, whilst having home visits by the General Practitioner and a non-Government primary care nursing service in order to meet their needs. PCQ recommends the Government consider extending access to *The Viewer* to private hospitals with shared care agreements, primary care providers and residential aged care facilities (with appropriate safeguards in place).

In addition to the above, PCQ believes providing General Practitioners access to *The Viewer* will assist in the communication of advance care planning documents across primary, secondary and tertiary care settings. Advance care planning is a process to help people to formulate and communicate their preferences regarding care during future incapacity. Advance care planning gives the person the opportunity to determine the likely scenarios coming towards the end of their lives, including the treatment they receive and the way they would like to be cared for.³ Recognition and accommodation of preferences expressed in advance care planning documents limit the application of burdensome treatments and allow individuals to have control over the level of healthcare they receive at the end of life.⁴ Furthermore, the advance care planning process improves patient and family satisfaction with end of life care and reduces stress, anxiety and depression in surviving relatives.⁵

PCQ endorses the Palliative Care Australia Position Statement on advance care planning⁶ and believes:

- Dying is part of life.
- Quality end of life care is realised when it meets the person's needs and *upholds their care preferences*.
- Advance care planning provides a *mechanism* to improve the quality of end of life care for people. It enables the coordination of their desired access to resources and services, to match their anticipated care needs.
- Advance care planning offers everyone, and especially people living with a terminal condition, their families and significant others the opportunity to *take control of decisions which affect their care*.
- Advance care planning should not be considered only relevant to people nearing the end of life but be considered by everyone. It should be considered as an *ongoing conversation* between the individual, their care team and as appropriate their family, significant others and carers.
- All Australians should be supported to consider and provided the opportunity to specify the type of care they would like to receive at the end of life. Continual reassessment of current circumstances and likely future scenarios are part of this consideration.
- Advance care planning should be applied and promoted across the health sector. Facilitating end of life discussions and supporting and engaging in advance care planning is the responsibility of the whole health care system, and should engage all members of the care team. It is not the exclusive domain of any particular health care sector or setting.

- Health workers across all levels of the health system should be skilled and educated to engage in end of life care discussions and advance care planning with patients and their families, significant others and carers. Specialist palliative care providers have expertise to support all involved in advance care planning.
- Promoting awareness of end of life options and engaging in end of life care discussions and planning is not the singular responsibility of the health care system but should also be considered a responsibility of the community and the individual.
- The role of *substitute (or proxy) decision makers* needs to be promoted.
- Formalised *advance care directives* can form an integral part of the advance care planning process for those who wish to develop one, serving as a vehicle for decisions about the type and level of medical intervention people wish to receive at the end of life. Care needs to be exercised to ensure that people fully understand and consent to the provisions of their advance care directives.

Whilst advance care planning is widely promoted across most Hospitals and Health Services in Queensland, access to documents (such as Advance Health Directives and Statements of Choices) is not easily accessible by all care providers. Many Hospital and Health Services routinely upload completed advance care planning documents to The Viewer. At present care providers, outside of Queensland Health, including Queensland Ambulance Service rely on patients and their families to provide such documents when needed.

PCQ continually receives anecdotal reports from members about people receiving care they did not want, despite having completed advance care planning documents. Reasons cited often include the lack of access to such documents by primary care providers and emergency responders. PCQ hopes that providing General Practitioners with access to *The Viewer* will assist in communicating the wishes of patients receiving palliative care, and ensure such wishes are met. PCQ also recommends that the Government consider extending access to *The Viewer* to private hospitals with shared care agreements, primary care providers and residential aged care facilities (with appropriate safeguards in place).

2. PCQ does not support streamlining the existing process relating to disclosure of confidential information for research purposes where the adult patient is unable to consent to the disclosure of information.

PCQ understands the following:

- The proposed amendments permit “*designated persons*” and “*prescribed health practitioners*” to disclose what would otherwise be strictly confidential health information about patients within prescribed guidelines and to access a database containing such information where such information is necessary for the treatment of a patient.
- Disclosure can occur where the CEO authorises such disclosure, where such disclosure is necessary to protect a child or where the CEO otherwise authorises it in writing. Disclosure

can also occur where the CEO gives written approval to a researcher to carry out research. A designated person can also disclose such information to a researcher.

At this stage, PCQ is concerned that the Regulations which will accompany the Act are not available for review, specifically whether the Regulations provide more stringent guidelines on the use of the confidential information or indeed who can become a designated person. Whilst the Bill lists a long list of people who can become designated persons, there is no detail available regarding how the process of selecting a designated person will be carried out, and what persons are (or should be) excluded from being selected. This is an important detail, as the magnitude of the potential for patient harm (via the disclosure of personal health information) is high and whilst the Minister talks about “appropriate safeguards”, the details are lacking.

From PCQ’s point of view, the amendments of the Act which relate to the disclosure of information where patients are unable to consent to such disclosure is an important feature. This amendment is likely to intersect and potentially come into conflict with elderly patients who have General Powers of Attorney. Whilst the Bill addresses this issue by requiring that the “substituted decision maker” must consent to such disclosure of information, there is potential there for practical conflicts to arise between the health practitioner and the substituted decision maker.

PCQ recommends that the Government publish further detail in relation to the above prior to amending the *Hospital and Health Boards Act (2011)*.

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References:

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3. Palliative Care Australia, Standards for providing quality palliative care for all Australians, PCA, Canberra, 2008
4. Silvester, W et al (2012) ‘Quality of advance care planning policy and practice in residential aged care facilities in Australia’ BMJ Supportive and Palliative Care

5. Detering K M et al (2010)'The impact of advance care planning on end of life care in elderly patients: randomised controlled trial' BMJ 340: c1345
6. Palliative Care Australia, Advance Care Planning Position Statement, PCA, Canberra