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Response to the Productivity Commission's Draft Report on Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services

Thank you for the opportunity to make this submission to Human Service Reforms. The focus of this submission is End of Life Care. As a team of experienced professionals with combined skills in planning, delivery, education, research and quality of end-of life care, in the community as well as in the acute sector, we support the proposed reforms for end of life care. The report well describes the current state of end of life care in Australia. In South Australia, the inequity in accessing quality end of life care for people who are dying requires significant reform. As the report correctly identifies, there are many gaps and inequities in palliative care services, access is often difficult and the fragmentation of services means many people die in the acute care setting and in the community without adequate palliative care. Even where there is access to highly skilled palliative care providers, the plan of care to support a person who wishes to die at home can fail due to a lack of coordination in person-centred planning and resources across health sectors.

Draft Recommendation 4.1 - Community-based palliative care

“State and Territory Governments to ensure that people with a preference to die at home are able to access support from community-based palliative care services to enable them to do so.”

Quality end of life care requires a collaborative approach based upon effective teamwork and communication in partnership with the patient and their substitute-decision-maker, family/carer. Once a plan of care is developed, a team approach and effective and responsive systems to enable and respond to the dynamic needs of the patient and family/carer alongside systems for quality improvement and effective clinical governance is necessary, but frequently does not happen.

Strategic reform needs to design in a collaborative interdisciplinary team approach across sectors for to achieve quality outcomes. The recipient of care or the clinicians coordinating care must often intersect and navigate services across multiple service providers, accessing multiple funding

streams. This may include acute, primary, aged care in public, private, and/or non-government organisation sectors. This complexity creates multiple failure points where even the best planned care and practitioners, can fail due to the failure of one component (for example access to required equipment such as a hospital bed in the home, palliative medication in a local pharmacy, or lack of a systems or provider to provide “intermittent response to an escalation in care needs).

Mapping community-based palliative care to reveal gaps is a first and important step, however, the mapping requires identification of the potential failure modes at those intersections (with consumers and clinicians). In the method of mapping and commissioning of community palliative care services, a process to ensure integrated, collaborative care to achieve quality outcomes across sectors should be included. The silos and inequity in care of the dying should no longer stand in the way of a person’s right to die in comfort and with dignity.

Further, it may be valuable to consider the six principles for development of new models of care developed by the National Health Service:

- “• Care and support is person-centred: personalised and empowering
- Services which are created in partnership with citizens and communities
- Focus is on equality and narrowing health inequalities
- Carers are identified, supported and involved
- Voluntary, community, social enterprise and housing sectors as key partners and enablers
- Volunteering and social action are recognised as key enablers.”

(P. Jones, The National Health Service Commissioning Board, December 2015, New Care Models: empowering patients and communities - A call to action for a directory of support, p.8, <https://www.england.nhs.uk/wp-content/uploads/2015/12/vanguards-support-directory.pdf>)

The West Australian Silver Chain model and the NHS-funded Birmingham Connected Palliative Care Hub are worthy of exploring further.

National Safety and Quality Health Service Standards, version 2, (NSQHCS v2) that address End of Life Care should apply to this sector in the context of this health care setting, along with standards to ensure effective collaboration between partners in care, and clear clinical governance for services provided across sectors. Funding models should reward effective collaboration and continuity of care, including across health sectors and in an interdisciplinary team based approach.

We agree with the concept of Government stewardship and that substantially increasing the availability of community-based palliative care is an absolute priority in order to meet demand. This will go a long way towards enabling the fundamental consumer choice of site of care. Increased, well-equipped and trained resources will facilitate earlier recognition of end-of-life, thereby encouraging advance care planning and reducing unwanted and non-beneficial medical

interventions. It is clear that aspects of this reform will take time and in the meantime, care in acute hospitals and aged care requires emphasis.

The disability care sector is worthy of specific mention. Care of dying people in this sector is largely provided by care workers who are unable to provide medication as required, especially by any route other than orally. The resident often requires transfer to hospital for terminal care for this reason. This is traumatic for everyone involved, as there is often no way to explain what is happening to the resident.

Draft recommendation 4.2 - End-of-life care in residential aged care

“The Australian Government to remove current restrictions on the availability and duration of funding for palliative care in residential aged care, and provide sufficient additional funding to ensure that people living in residential aged care receive end-of-life care that aligns with the quality of that available to other Australians.”

The residential aged care sector, where a large percentage of elderly Australians die, should have access to adequate skilled staffing levels to provide proper care at the end of life. Many elderly people dying with multiple organ failure may not require specialist palliative care, but have the right to appropriate nursing, spiritual care, and proper pain relief, all of which are encompassed in a palliative care approach. The number of transfers to the acute hospitals because of inadequate staffing and access to appropriate care can be considered to be a failure in our system of care at the end of life. Those who die when old, have equal rights to be cared for with dignity and respect.

This recommendation is strongly supported. It should be accompanied by congruence with (NSQHCS v2) and changes to the Aged Care Accreditation requirements, along with standards to ensure effective collaboration between partners in care, and clear clinical governance for services provided across sectors. Funding models should reward effective collaboration and continuity of care and provide for flexibility in health care team roles to achieve quality outcomes. Importantly, care models should ensure a person-centred approach, with care planned in line with a dying person’s wishes. Innovation could be focused on developing multi-disciplinary capacity in the aged care workforce to lead quality end of life planning and delivery.

Advance care planning

Draft recommendation 4.3 -

“The Australian Government to: include initiating an advance care planning conversation as one of the actions that must be undertaken to claim the ‘75 plus’ health check Medicare item numbers.

Introduce a new Medicare item number to enable practice nurses to facilitate advance care planning.”

We support both of these recommendations as advance care planning and advance care directives are now well recognized tools for people to express their wishes and values about their care at the end of their life, should they lose the ability to make decisions when they are dying.

It is also important that if people wish to die at home, and express this in their advance care directive, that there is choice for them to do so. With the fragmentation of services in the community in South Australia, it is increasingly difficult for people to find or access services to care for them at home.

The 75 plus health check is one good trigger point, however advance care and resuscitation planning in people with chronic life-limiting diseases needs to be designed into best practice clinical pathways and communication systems.

Respecting a person wishes rather than treating aggressively and often inappropriately at the end of life is an important aspect of good medical practice. Applying life sustaining measures, including resuscitation, at the end of life has become common practice and there is a need to change this culture to align better with the values and wishes of the person and the community in end of life care. It is important that health professionals understand when to stop treatment and focus on good end of life care.

The use of triggers to prompt discussion on goals of care is a key step. There is a need to build capacity of the workforce to identify triggers and conduct end of life conversations. Reform initiatives can support this through incentives that promote incorporation the use of trigger tools in clinical processes of care and into health professional education programs.

The introduction of a Medicare item number to enable social workers to facilitate advance care planning and support would also add considerable depth and choice to the consumer experience. Community based care in particular, has significant and wide-ranging impacts upon social networks, and when poorly assessed and managed, often result in unwanted transfer into the acute hospital sector. Psychosocial care is often given less emphasis than physical care because of funding issues.

Clinical placement of health professionals may fail to provide learning experiences for doctors, nurses and allied health professionals to obtain skills in recognizing a person at end of life, observe end-of life discussions with family, or participate in the care of a person/family/carer and at the time of death. Reforms will need to consider building capacity within the workforce to enable identification of a person at the end-of-life and the skills to partner with consumers to discuss and plan care in respect to a person's wishes.

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There is value in engaging with consumers and community to innovate new mediums and methods to support people in end-of-life planning and processes. Public health literacy in end-of-life planning requires support. Emerging practices and technology such as My Health Record, web based applications and discussion forums, methods to engage with CALD and ATSI groups to allow for equity is required.

Draft recommendation 4.4-

“The **Australian Government** to include the facilitation of ongoing conversations about advance care planning in the aged care Quality of Care Principles.”

This recommendation is strongly supported, also see related comments in response to Draft Recommendation 4.3

Draft recommendation 4.5 – Better Data on End-of-Life Care

“The **Australian, State and Territory Governments** to ensure there is sufficient data to enable them to monitor how well end-of-life care services are meeting users’ needs.”

This recommendation is strongly supported. Whilst the measures proposed are baseline, there will also need to be agreed measures for quality.

Sincerely,

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