



**Faculty of Health, Deakin University**

## **Non-informed choice is no choice at all**

Response and Comment to 'Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services', Draft Report. July 2017

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Institute for Healthcare Transformation,  
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By email:

**Dear Commissioners,**

**Issue Paper Response:**

The Institute of Healthcare Transformation and the Centre for Organisational Change in Person-Centred Healthcare, Faculty of Health, Deakin University welcomes the Productivity Commission's inquiry into Australia's Human Services, and we look forward to engaging with the Commission during the remainder of this inquiry.

**The new Deakin Institute for Healthcare Transformation works to accelerate the translation of existing and emerging evidence into practical solutions to improve health outcomes and end-of-life-care.**

The Institute aims to deliver cutting edge health systems research, nationally and internationally, positioning Deakin University as the premier Victorian and Australian resource for health systems research, and a leader in healthcare reform.

This outward facing collaborative initiative aims to leverage and showcase the University's research strengths in health, building the necessary scale and scope to support world-class health systems research, eHealth and health innovation.

The Institute will link researchers from diverse disciplines with a common focus on health by establishing multi-disciplinary collaborative approaches both within Deakin and across external partner organisations.

By connecting leading researchers in health with experts in information technology, data analytics, engineering, environmental studies, and economics, we can design innovative solutions to solve our most pressing global health challenges.

**The Centre for Organisational Change in Person-Centred Healthcare has been developed for both consumers and health professionals. We provide education and training and use translational research to influence change in policy and the culture of healthcare systems.**

Organisational change is achieved through collaborative, innovative, inter-professional implementation research and education. In simple terms we must translate existing knowledge into everyday clinical practice.

To facilitate this, we offer tailored educational programs for health professionals and consumer groups to foster person-centred healthcare. Underpinned by established educational frameworks, our programs are learner-centred and evidence-based.

Our Faculty comprises experienced clinician-educators, skilled in small-group experiential learning, ensuring training that is both clinically applicable and effective.

Yours sincerely,

**Rebecca Bartel**

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## Executive Summary

### Non-informed choice is no choice at all.

The way people are cared for when they are dying is important. End-of-life care impacts everyone, at every age - the living, the dying and the bereaved. It is not a response to a particular illness or condition. It is not limited to a particular group or section of the community.

#### **When it comes to death the statistics are clear. We will all die.**

We assume that we will always have control of our care decisions. However, many people nearing the end-of-life are not physically or cognitively able to make their own care decisions, and their choices and wishes remain unknown. This means too many people are dying in a way they wouldn't choose, and too many of their loved ones are left feeling bereaved, guilty, and uncertain.

The care most Australians receive at the end-of-life often does not reflect their values, goals, or informed choices.

The majority of Australians say they would prefer to die at home, however most will die in a care institution, such as a hospital intensive care unit. Dying has become institutionalised, and evidence shows there is a significant mismatch between what people most often say they want (supportive services) and the services they actually get (acute care). Acute health systems are focused on providing treatment and cure - increasing survival and reducing mortality. For patients who are at the end-of-life, this can result in the delivery of care that is inappropriate, inadequate or futile. People frequently endure unwanted aggressive, costly treatments and suffer from insufficient management of symptoms such as pain and shortness of breath.

Reports and investigations too frequently identify poor end-of-life care. Access to care is largely determined by age, diagnosis and geography rather than individual need. It is often characterised by fragmented care systems; poor communication among doctors, patients, and families; and enormous strains on family caregiver and support systems. It can create significant moral distress for health professionals working in these systems, especially for those who recognise that the care they provide in some cases is not what they would want for themselves or for their families.

There is, however, a simple yet significant way to improve this care. The road map to reform starts with a conversation.

End-of-life conversations improve end-of-life care, patient and family satisfaction and reduce stress, anxiety and depression in surviving relatives. These conversations offer people the opportunity to define their goals and expectations for the personal, medical, emotional and spiritual care they want to receive at the end of their life. Conversations emphasising patient choice, including treatment preferences, are a powerful determinant of care. Patients are more likely to receive care that is consistent with their choices when they have had the opportunity to discuss their choices for end-of-life care with their loved ones as well as a health professional. Patient conversations with health professionals are a better predictor of patients' end-of-life care outcomes than the place they are being treated.

Not everyone will want to talk about the end of their life, but the ‘right conversations, with the right people, at the right time’ can enable a patient and their loved ones to make the best use of the time that is left and prepare for what lies ahead.

Overwhelmingly, there is recognition that open conversations about death, dying and bereavement play a fundamental role in the:

- Changing of attitudes towards death and dying
- Successful planning and delivery of person-centred choice in End-of-life Care
- Quality of end-of-life care
- Availability of support for the bereaved, and
- Long-term health and well-being of individuals and communities.

Public awareness, engagement and community development work on dying, death, and end-of-life care are increasingly identified as priorities in government health strategies and policies worldwide. Policymakers, health systems and palliative care services are seeing conversations as important areas of action to improve end-of-life experiences. Countries such as England, Scotland, Ireland, Canada and the US are implementing public awareness campaigns to promote end-of-life care conversations so that people are aware of ways to better live with death, dying and bereavement.

End-of-life care has a low profile in Australia. It is not recognised as a public health concern, and we lack the national awareness and engagement programs evident in other countries. Our impressive global record of health promotion and public education is not being matched in the process of dying, death or bereavement.

Unless we take personal, professional, and political action, we will not be able to afford to die with dignity in the future. For multiple reasons that include an ageing population, escalating healthcare spending, and an approach to end-of-life care that often does not conform to the wishes of patients, we cannot delay action.

We present three priority simple, cost effective amendments to the Productivity Commission Draft Report:

#### **RECOMMENDATION 1: Shared Decision Making**

**The Australian Government to ensure that health professionals (including GPs, Nurses and Specialists from a range of specialist colleges) have the opportunity to have evidence based communication skills training that underpin effective conversations about shared decision making, end-of-life care and that drive a culture of person-centred healthcare.**

#### **RECOMMENDATION 2: Public Awareness Campaign**

**The Australian Government to fund a well-considered and integrated public awareness campaign on death, dying and end-of-life conversations, as part of a suite of reforms, aimed at improving death literacy and facilitating community behaviour change.**

#### **RECOMMENDATION 3: Adequate Remuneration for End-of-life Conversations**

**The Australian Government to adequately remunerate GPs, RACFs and essential services to have end-of-life conversations to prevent unnecessary usage of emergency and acute care services. These conversations should be undertaken by competent and skilled professionals, at a time when the patient is ready (or on admission to a RACF) and earlier than the 75 plus health check.**

# 1. Shared Decision Making Critical for Informed User Choice

We agree with the Commission's view (p.113-114), an effective system of end-of-life care would put users' choices at the heart of end-of-life care services and that

*"A comprehensive approach to end-of-life care recognises that the patient and clinicians are both essential participants in discussions and decision-making about care needs at the end-of-life . This shifts the emphasis of care delivery from life extension toward care that attempts to fulfil each patient's choices, values and preferences, given the realities of the patient's clinical condition and treatment options.'*

In order to achieve this, the Commission has recommended a number of proposed reforms designed to put users' needs and choices at the heart of end-of-life care services (table 4.1).

However, one critical element is missing. Before we can take any of the well documented steps, first we need to first train clinicians how to have discussions and to undertake shared decision making with patients.

## Shared Decision Making

Shared decision making supports patient-centred care and ensures the appropriateness of care. Shared decision making is one of those rare things that you can argue positively affects all three targets of better healthcare and end-of-life care:

- improving the patient & carer experience (including more empowered consumers)
- improving quality of life at the end-of-life
- lowering care costs.

Shared decision making involves the integration of a patient's values, goals and concerns with the best available evidence about benefits, risks and uncertainties of treatment, in order to achieve appropriate healthcare decisions.<sup>1</sup>

It involves clinicians and patients making decisions about the patient's management as partners. Patients and clinicians have different expertise when it comes to making consequential clinical decisions. While clinicians know information about the disease, tests and treatments, the patient knows information about their body, their circumstances and how their values and goals influence their end-of-life care preferences.

In partnership with their clinician, patients are encouraged to consider all the available treatment options, not just the clinician's preferred option, and the likely benefits and harms of each, to communicate their preferences, and help select the course of action that best fits these.

Shared decision making is of increasing interest to policy makers and international researchers. Current research undertaken by the Australian Commission on Quality and Safety in Healthcare (ACSQHC ) indicates:<sup>1</sup>

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<sup>1</sup> Australian Commission on Quality and Safety in Healthcare. Shared Decision Making. 2017 Available online at <https://www.safetyandquality.gov.au/our-work/shared-decision-making/> (Accessed 7 July 2017)

- patients are less informed and involved in making decisions about their health care than they would like to be
- shared decision making can improve satisfaction with care and leads to better quality decisions
- patients using evidence-based decision aids have improved knowledge of the options, more accurate expectations of possible benefits and harms, and feel that they had greater participation in decision making than people receiving usual care
- better-informed patients make different, often more conservative, less costly choices about treatment, because, it is thought, that information provides a realistic appreciation of likely benefits and risks of treatment and enables decisions about the potential outcomes in a more considered and less regretful way.

In addition, studies show it leads to considered decisions, happier and more engaged patients and lower overall costs.<sup>2,3,4,5,6</sup> Other desirable outcomes include a more effective trusting professional relationship between patients and clinicians. Other outcomes include more clarity for other members of the wider treatment team and thus less risk of unwanted burdensome interventions such as surgery close to the end-of-life .

### Why Isn't Shared Decision Making Used Widely?

Perhaps, it shouldn't be surprising that evidence based shared decision making isn't used more widely. It is dependent on the clinicians having the requisite consultation skills, the healthcare organisations to have embedded systems in place, and a shift in the traditional relationship between patients and clinicians.

Shared decision making is not just about explaining treatments to patients and asking their opinions. It is a more rigorous process that takes training and commitment to succeed. It requires the use of decision aids, resources that inform patients of the benefits and drawbacks of healthcare options and helps guide them to decisions. It is predicated on a wide variety of clinicians acquiring core consultation skills that facilitate this approach becoming standard clinical practice.

Shared decision making is more easily endorsed than implemented. Not every clinician thinks it's necessary to fully inform patients or give them a voice in medical decisions. Health professionals require training and successful implementation of shared decision making requires a clinical champion to push for it and a familiarity with how decision aids work.

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<sup>2</sup> Elwyn, G. Shared Decision Making and Motivational Interviewing: Achieving Patient-Centered Care Across the Spectrum of Health Care Problems. *Ann Fam Med* 2014;270-275.

<sup>3</sup> Cardona-Morrella, M et al. A systematic review of effectiveness of decision aids to assist older patients at the end-of-life . *Patient Education and Counseling* 2017, 425-425.

<sup>4</sup> Shepherd, HL, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial. *Patient Education and Counseling* 2011, 379-385.

<sup>5</sup> Shepherd, HL, et al. Can consumers learn to ask three questions to improve shared decision making? A feasibility study of the ASK (AskShareKnow) Patient – Clinician Communication Model® intervention in a primary-healthcare setting. *Health Expectations* 2015.

<sup>6</sup> Street, RL et al. How does communication heal? Pathways linking clinician–patient communication to health outcomes. *Patient Education and Counseling* 2009, 295-301.



Other obstacles included physicians' tendency to be authoritarian, and patients' fear of being perceived as "difficult," possibly to the detriment of the relationship with their clinician and the quality of care they receive. It needs to be tailored to each individual patient; one size will not fit all.

Patient reluctance can be overcome with good decision aids with correct information that are embedded in a systemic whole of organisation approach, patience and prompting from their health professionals.

More than aids, successful shared decision making requires health professionals to consider their patients as more than just people to be treated, but individuals who have an equal say in how they're treated.

### Increasing Shared Decision Making In End-of-Life Care

There is a major missing piece here from the literature that clinicians across the board are not having the end-of-life conversations with patients and carers and do not feel skilled or equipped to do so.

At the moment, however, there are limited opportunities to gain these skills. This is clear in advanced cancer and chronic illness already.<sup>7,8,9,10</sup>

We need to educate health professionals nationally and provide them with the skills and experience required to be competent so they can be confident in sharing in the decision-making tasks.

As a minimum they require communication skills, skilled decision making processes to help guide them through the choices, as well as understand health literacy.

Deakin University has recently established the **Centre for Organisational Change in Person-Centred Healthcare**. Its primary focus is on achieving organisational change through collaborative education and research in clinical communication. We aim it to be the country's preeminent research / education program for the rigorous study of health care decision making.

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#### RECOMMENDATION 1: Shared Decision making

**The Australian Government to ensure that health professionals (including GPs, Nurses and Specialists from a range of specialist colleges) have the opportunity to have evidence based communication skills training that underpin effective conversations about shared decision making, end-of-life care and that drive a culture of person-centred healthcare.**

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<sup>7</sup> Nicolai, J et al. When do cancer patients regret their treatment decision? A path analysis of the influence of clinicians' communication styles and the match of decision-making styles on decision regret. *When do cancer patients regret their treatment decision? Patient Education and Counseling* 2016, 739-746.

<sup>8</sup> Pardon, K et al. Are patients' preferences for information and participation in medical decision making being met? Interview study with lung cancer patients. *Palliative Medicine* 2016 25(1) 62-70

<sup>9</sup> Henselmans, I et al. Shared decision making about palliative chemotherapy: A qualitative observation of talk about patients' preferences. *Palliative Medicine* 2016, 1-9

<sup>10</sup> Clayton, JM, et al. Randomized Controlled Trial of a Prompt List to Help Advanced Cancer Patients and Their Caregivers to Ask Questions About Prognosis and End-of-Life Care. *J Clin Oncol* 25:715-723.

## 2. Conversations a Critical Part of Advance Care Planning

Overwhelmingly, there is recognition that skilled conversations about death, dying and bereavement play a fundamental role in the:

- Changing of attitudes towards death and dying
- Successful planning and delivery of person-centred choice in End-of-life Care
- Quality of End-of-life Care
- Availability of support for the bereaved, and
- Long-term health and well-being of individuals and communities.

Throughout our lives, but especially when we are older and facing increased risk of serious illness, we need a plan about what services are essential to living well and meaningfully.

As Australia ages, holding conversations about preferences for care is paramount. Most often with family present, older Australians do engage in end-of-life conversation, if given the opportunity to reflect and share. Those who have had this conversation are almost three times as likely to have their end-of-life wishes both known and followed, and their family members demonstrate less anxiety, stress, and depression during bereavement.<sup>11</sup>

Patient conversations with health professionals are a better predictor of patients' end-of-life care outcomes than the place they are being treated. Not everyone will want to talk about the end of their life, but the 'right conversations, with the right people, at the right time' can enable a patient and their loved ones to make the best use of the time that is left and prepare for what lies ahead.

### Clarification on Advance Care Planning

On page 12 the Commission states, 'to ensure a real choice people will often need to communicate their wishes ahead of time using an advance care plan (ACP).' This is incorrect.

High quality advance care planning is dependent upon a number of end-of-life conversations and that communication being person-centred, individualised and aligned with the context. The quality is related to the skill of the clinicians and not just about the quality of legislation or documentation.

**Advance care planning is a process and not an outcome.** Advance care planning is a process of communication between individuals, families, and others who are important to the discussion, as well as healthcare providers, to understand, discuss, and plan future health care decisions, not only to lay preparations in the event that an individual loses decision-making capacity, but also to offer detailed instruction about values and wishes. It is about planning and talking about the 'what ifs' that might occur across the entire lifespan. The goal is to try to engage in conversations more proactively rather than just reacting to changes in health conditions.

Multiple and skilled end-of-life conversations are a critical part of the advance care planning process. The output of an advance care plan, directive or document *per se* is not the critical element. What is important is the process of having the opportunity to have numerous discussions with loved ones

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<sup>11</sup> Detering, K.M.; Hancock, A.D.; Reade, M.C.; Silvester, W. The impact of advance care planning on end-of-life care in elderly patients: Randomised controlled trial. *BMJ* 2010, 340, c1345

and suitably skilled professionals that facilitate good end-of-life care planning; advance care plans / documents are only one part of that of that process.

Advance care plans (ACP) and advance care directives (ACD) are only one part of the advance care planning process; that is, a written formal or legal document that addresses plans about what treatment people wish to have or not have when they near death. These statements can include expectations about what people may wish to refuse to have, such as cardiopulmonary resuscitation, artificial ventilation, or artificial nutrition/feeding; they can also be positive preferences such as what they would like to experience when they are near death, such as being at home with a loved one, preserving dignity and worth, and leaving a legacy. In addition, this process should involve the identification of a surrogate decision-maker, who will honour, uphold, and respect a person's preferences. However, these documents go into effect only when a person is incapacitated and loses the ability to speak for themselves. While there is a lack of evidence that ACP documentation leads to engagement of healthcare professionals in end-of-life discussions, these documents should be viewed as a 'living document' that should be revised and adjusted over time, as situations change, including change in health status.

Focus on conversations rather than documentation will encourage people to consider what constitutes a 'good death' for them personally, including identifying what factors are considered important (i.e., achieving a sense of control, leaving a legacy, maintaining a sense of dignity, being without pain or symptoms, relieving financial burdens, strengthening close relationships, and saying important things), and for informally communicating their future wishes.<sup>12</sup> We argue that embedding these conversations into lay communication will 'normalise' death and dying into both clinical and mainstream dialogue.<sup>13</sup>

## The Advance Care Planning Process

In the US, the National Framework and Preferred Practices for Palliative and Hospice Care Quality (NQF) shows that optimal advance care planning is not a one-time event, but an ongoing series of conversations at critical milestones throughout the life cycle.<sup>14,15</sup>

Within this framework, the advance care planning process comprises five distinct phases, from pre-contemplation to action and maintenance, which includes the completion of a written advance care plan or a directive.

**Conversations take time and effort and cannot be completed as a single checklist; they need to take place on more than one occasion.**

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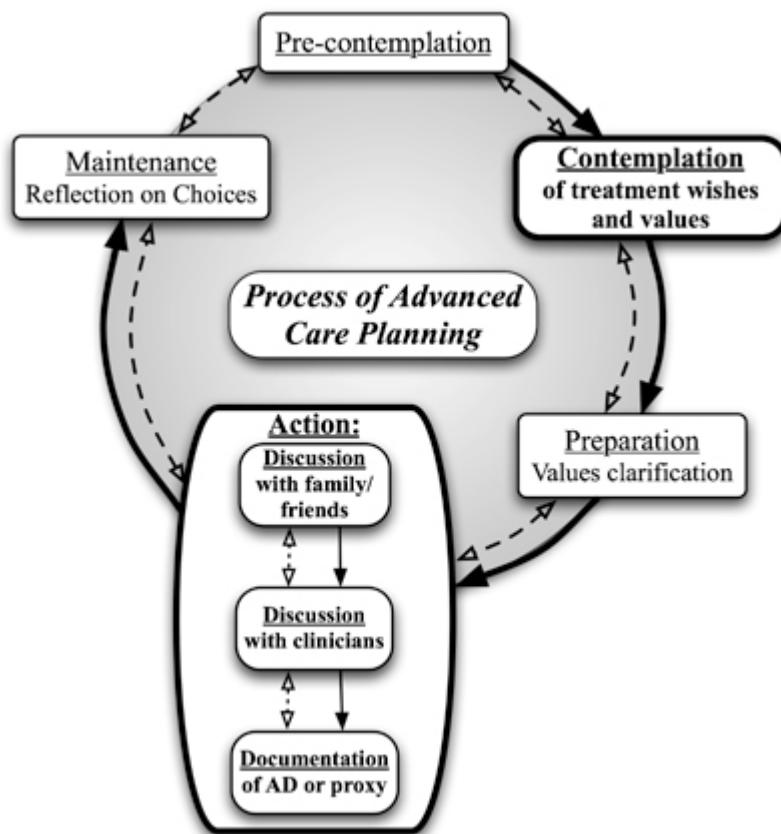
<sup>12</sup> Steinhauer, K.E.; Christakis, N.A.; Clipp, E.C., et al. Factors considered important at the end-of-life by patients, family, physicians, and other care providers. *JAMA* 2000, 284, 2476–2482

<sup>13</sup> Lewis, E.; Cardona-Morrell, M.; Ong, K.Y.; Trankle, S.A.; Hillman, K. Evidence still insufficient that advance care documentation leads to engagement of healthcare professionals in end-of-life discussions: A systematic review. *Palliat. Med.* 2016, 30, 807–824.

<sup>14</sup> National Quality Forum (NQF). A National Framework and Preferred Practices for Palliative and Hospice Care Quality. Available online: [http://www.qualityforum.org/Publications/2006/12/A\\_National\\_Framework\\_and\\_PREFERRED\\_Practices\\_for\\_Palliative\\_and\\_Hospice\\_Care\\_Quality.aspx](http://www.qualityforum.org/Publications/2006/12/A_National_Framework_and_PREFERRED_Practices_for_Palliative_and_Hospice_Care_Quality.aspx) (accessed on 7 July 2017).

<sup>15</sup> Benson, W.; Aldrich, N. Advance Care Planning: Ensuring Your Wishes Are Known and Honored If You Are Unable to Speak for Yourself. 2012. Available online: <https://www.cdc.gov/aging/pdf/advanced-careplanning-critical-issue-brief.pdf> (accessed on 7 July 2017).

Figure 1: Conceptual Model of the Advance Care Planning Process<sup>16</sup>



Source: Sudore, RL et al. *J Am Geriatr Soc* 56:1006–1013, 2008.

There are three relevant components to this series of ongoing end-of-life conversations:<sup>17, 18</sup>

1. A willingness of the individual to reflect. This involves a discussion aimed at defining values, life goals, and wishes about the future. Commonly, this is grounded in how one sees a “life well lived”.
2. An organised “coming together” of all persons who will be involved in honouring the wishes. Plain language, timing, and trust are key elements of the success of this meeting.
3. An ongoing discussion about the preferences, especially in light of the complexity of life-limiting and serious illness, must be engaged in.

It has been suggested that advance care planning should be recognised as a health behaviour and that the most effective way to engage people in this process is to tailor the information to a person’s readiness for engagement.<sup>19</sup>

<sup>16</sup> Sudore, RL; Schickedanz, AD; Landefeld, CS; Williams, BA et al. Engagement in Multiple Steps of the Advance Care Planning Process: A Descriptive Study of Diverse Older Adults. *J Am Geriatr Soc* 56:1006–1013, 2008. Weathers, E.; O’Caoimh, R.; Cornally, N.; Fitzgerald, C.; Kearns, T.; Coffey, A.; Daly, E.; O’sullivan, R.; McGlade, C.; Molloy, D.W. Advance care planning: A systematic review of randomised controlled trials conducted with older adults. *Maturitas* 2016, 91, 101–109.

<sup>17</sup> Wittenberg-Lyles, E.; Goldsmith, J.; Oliver, D.P.; Demiris, G.; Kruse, R.L.; Van Stee, S. Using medical words with family caregivers. *J. Palliat. Med.* 2013, 16, 1135–1139.

<sup>18</sup> Fried, T.R.; Bullock, K.; Iannone, L.; O’leary, J.R. Understanding advance care planning as a process of health behavior change. *J. Am. Geriatr. Soc.* 2009, 57, 1547–1555

## Public Awareness Campaigns on Death and Dying

**Death and dying is everyone's business. It takes a village to raise a child and it takes a community to support death, dying and bereavement.**

*Julian Abel, British Medical Journal, 2016*

Awareness campaigns are organised communication activities designed to raise awareness, induce behaviour change and improve quality outcomes for individuals and populations.

We respectfully disagree that public awareness campaigns can only ever be small part of the solution as the draft report from The Commission states on p 135:

*Many inquiry participants advocated public awareness campaigns to encourage people to talk about death and dying and to increase awareness of advance care planning. But public awareness campaigns can only ever be small part of the solution in this space. Unlike, for example, road safety, where people can act independently in response to messages about safer driving, there is little evidence that awareness on its own inspires and equips people to have difficult conversations and write plans for a future they are reluctant to imagine (Ramsaroop, Reid and Adelman 2007).*

It is naïve to believe good public awareness programs like Australia's very effective road safety campaigns are driven by community awareness alone. There are a wide range of issues related to the strategic design of these campaigns, which also had implications for cost effectiveness. The successful campaigns were part of a targeted, well-crafted, integrated communications and behaviour change program which employed a range of persuasive tools, emotional messages, incentives and penalties, communication tools and policy / legislation programs to drive systemic change.<sup>20</sup> The issues regarding the legal status of the target behaviour, and any associated enforcement, added further complexity and strategic impact to both the development, outcomes and evaluation of the public campaigns. These campaigns were also based on explicit theoretical models and prior qualitative or quantitative research which informed the campaign development.

The systematic review by Ramsaroop, Reid and Adelman<sup>21</sup> demonstrated statistically significant effects associated with the advance care directive intervention. They also emphasised that the most successful interventions incorporated direct patient-healthcare professional interactions over multiple visits. It is not surprising, that ad hoc, passive education about written plans (and success measures of directive or plan completion rates) had little impact.

The Australian experience is consistent with this, i.e. uptake of advance care plans is low in Australia despite passive, inconsistent, ad hoc promotion by government related organisations in Australia.

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<sup>19</sup> Fried, T.R.; Redding, C.A.; Robbins, M.L.; Paiva, A.L.; O'leary, J.R.; Iannone, L. Development of personalized health messages to promote engagement in advance care planning. *J. Am. Geriatr. Soc.* 2016, 64, 359–364

<sup>20</sup> Delaney, A; Lough, B; Whelan, M; Cameron, M. A Review of Mass Media Campaigns in Road Safety. Monash University Accident Research Centre 2004.

<sup>21</sup> Ramsaroop SD, Reid MC, Adelman RD. Completing an advance directive in the primary care setting: what do we need for success? *J Am Geriatr Soc.* 2007 Feb;55(2):277-83.

The reasons behind the low level of uptake of plans in Australia is thought to be related to the lack of societal awareness and understanding of end-of-life care and the value of a plan, as well as lack of health professionals' involvement in planning a result of time pressures, financial disincentives and inadequate education and training in end-of-life care.<sup>22</sup>

For a public awareness campaign to work it must incorporate behaviour change interventions including education, training, and enablement in the context of collaborative team-based approaches and other elements we know are effective to change practice of both healthcare professionals and the wider population.

Advocates of a public awareness campaign for end-of-life conversations and advance care planning, including our original recommendations, support an integrated public health campaign including behaviour change interventions so people can build their death literacy to be able to act independently in response to messages about end-of-life care conversations.

### **End-of-Life Care is a Public Health and Health Systems Problem**

Achieving quality end-of-life care is a public health and health systems problem. It is a public health problem because of the number of people it affects, directly and indirectly, in terms of the well-being of loved ones, and the large-scale, population based nature of some possible interventions. It is a health systems problem because one of its main features is the need for better information on quality end-of-life care.

The World Health Organization (WHO) recognises end-of-life care as a global public health issue and this is reflected at strategic level. Good quality care at the end-of-life is also recognised as a basic human right.<sup>23</sup>

The WHO recommends:<sup>24</sup>

1. Public health policy must acknowledge people's right to high-quality palliative care and to make decisions about it, whatever the nature of the disease they suffer from. These rights should be enshrined in health and social care legislation.
2. Policy-makers should monitor the wishes of seriously ill people concerning place of care and death.
3. Policy-makers should routinely monitor place of death as one interim measure of success of the system of palliative care provided.
4. Policy-makers should encourage the health services to inquire of people their preference for place of care and death. Meeting individual preferences should be the ultimate measure of success.

Despite this clear position, end-of-life care has a low profile in Australia. It is not recognised as a public health concern by the Commonwealth, and we lack the national awareness and engagement programs evident in other countries. Our impressive global record of health promotion and public education is not being matched in the process of dying, death or bereavement.

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<sup>22</sup> NSW Parliamentary Research Service May 2014 e-brief 6/2014 Advanced Care Directives. Available online <https://www.parliament.nsw.gov.au/researchpapers/Documents/advance-care-directives/Advance%20Care%20Directives.pdf> (Accessed 7 July 2017)

<sup>23</sup> As reflected in Article 25, United Nations Universal Declaration of Human Rights, 2001.

<sup>24</sup> WHO. The Solid Facts: Palliative Care, 2004. Available online: [http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0003/98418/E82931.pdf](http://www.euro.who.int/__data/assets/pdf_file/0003/98418/E82931.pdf) (Accessed 7 July 2017)

In the largest Australian survey on Attitudes Regarding End-of-Life Care (n=3000, people aged 16-94) undertaken by The Australian Centre for Health Research (ACHR) in 2016 showed:

- 89% of Australian adults surveyed do not think we talk about death and dying enough.
- 68% of Australian adults think they have had a conversation about end-of-life wishes – deeper analysis showed they have only had a conversation about ‘who should who should speak for them in an emergency’ and ‘whether they would like to be buried or cremated’.
- Australians tend to focus on practical issues such as making a will and an enduring power of attorney for property and finance, but less so on planning how to best prepare for dying itself.
- Australians want doctors to discuss end-of-life care & believe Medicare should cover the cost, but they want to talk to their families first.
- When asked what is one thing we can do to improve end-of-life care the first answer was to have open end-of-life care conversations and better communication.

**Overall, Australians want to talk about end-of-life care but feel they don’t have the tools or permission to talk about death.**

### **International Public Awareness Campaigns**

Public awareness, engagement and community development work on dying, death, and end-of-life care are increasingly identified as priorities in government health strategies and policies worldwide. Policymakers, health systems and palliative care services see conversations as important areas of action to improve end-of-life experiences and patient choice.

The Centers for Disease Control and Prevention (CDC) recognises the public health opportunity of advance care planning in order to improve their quality of care at the end-of-life, and recognise it as a critical part of healthy ageing.<sup>25</sup>

According to the CDC, advance care planning:

*“can potentially affect a large number of people, can reduce unwanted, futile, and expensive treatment, and can meet public demand to change the way care has been addressed in the past. Just as healthcare is not solely the responsibility of the sick but also the healthy, so too, dying and death are the responsibility of everyone, not simply those who are old or have serious illness.”*

Evidence from a systematic review also highlights the impact of community engagement in end-of-life care and can influence complex issues such as carer support, community capacity, wellbeing and social exclusion.<sup>26</sup> It has been demonstrated that engaging communities can lead to improved outcomes for carers such as decreased fatigue or isolation, increase in size of caring networks and that wider social networks can influence factors such as place of death and involvement of palliative care services.

Countries such as England, Scotland, Ireland, Canada and the US are actively implementing and expanding public awareness campaigns to promote end-of-life conversations. Some of these

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<sup>25</sup> Center for Disease Control and Prevention. Give Peace of Mind: Advance Care Planning. Available online: <https://www.cdc.gov/aging/advancecareplanning/about.htm> (accessed on 7 July 2017).

<sup>26</sup> Sallnow, L; Richardson H; Murray, SA, et al. The impact of a new public health approach to end-of-life care: A systematic review. *Palliat. Med.* 2015, 30, 200–211.

activities are documented below:

### **United Kingdom & Ireland**

There has been a good deal of development and research in the United Kingdom and they are considered the global gold standard. Death awareness and death literacy is not only more culturally transparent in the UK, but seems to be integrated into the context of everyday living. Through community engagement and social action, conversations about death and dying are commonplace and have set the stage for the development of a public health approach.<sup>27</sup> This public health approach is operationalised through community engagement, collaboration, and empowerment, and creates a template for a public health approach to advance care planning.

In England, a national coalition 'Dying Matters' was established in 2009 under the auspices of the National Council for Palliative Care and the promotion of an annual Dying Matter's week and the development of extensive information material and community education initiatives. In Scotland, 'Good Life, Good Death, Good Grief' is working to make Scotland a place where there is more openness so that people are aware of ways to live with death, dying and bereavement. The Irish Hospice Foundation (IHF) is a national charity dedicated to all matters relating to dying, death and bereavement in Ireland. Their community awareness program, 'Think Ahead', guides people to discuss and record their care preferences in the event of an accident, advanced illness or death.

### **United States**

The Institute for Health Care Improvement (IHI) supports 'The Conversation Project', a US public engagement campaign with a goal that is both simple and transformative to make sure that every person's wishes for end-of-life care are expressed and respected. 'The Conversation Project' offers people the tools, guidance and resources they need to begin talking with their loved ones, around the kitchen table, about their wishes and preferences.

The Institute of Medicine's (IOM) report on Improving Quality and Honoring Individual Preferences Near the End-of-life highlights the importance of public education and engagement,<sup>28</sup> recommendation 5 states:

*"Civic leaders, public health and other governmental agencies, community-based organizations, faith-based organizations, consumer groups, and professional societies, should engage their constituents and provide fact based information to encourage ACP and informed choice based on the needs and values of individuals. Public education and engagement efforts should aim to normalize these difficult conversations and to assist people in achieving the necessary information to have meaningful discussions about the values and goals of care"*

Much of this work was founded on the Open Society Institute's Project on Death in America which worked to understand and transform the culture and experience of dying and bereavement.<sup>29</sup> It

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<sup>27</sup> Lewis, E.; Cardona-Morrell, M.; Ong, K.Y.; Trankle, S.A.; Hillman, K. Evidence still insufficient that advance care documentation leads to engagement of healthcare professionals in end-of-life discussions: A systematic review. *Palliat. Med.* 2016, 30, 807–824.

<sup>28</sup> Pizzo, P.; Walker, D.; Bomba, P. *Dying in America: Improving Quality and Honoring Individual Preferences near the End-of-life*; Institute of Medicine: Washington, DC, USA, 2014.



encompassed diverse communities and cultures across the United States, as it sought to engage with complex ethical and legal issues and to tackle questions of public policy, finance, and professional regulation. The Last Acts Campaign aimed to bring death related issues out in the open and help individuals and organisations pursue better ways to care for the dying. The American Medical Association, with a grant from the Robert Wood Johnson Foundation, launched a program called Education for Physicians on End-of-Life Care project whose goal is to educate all physicians on the clinical competencies required to provide quality end-of-life care.

## **Canada**

The Ian Anderson Program on Quality End-of-Life Care was an extensive five-year initiative designed to improve end-of-life care at a health systems level throughout Canada.

In response to more recent data showing Canadians were not fully aware of palliative care and the majority had not taken steps to manage their own future care through the use of advance care planning tools, a public awareness campaign was launched.

The 'Speak Up' Campaign is part of a larger initiative, Advance Care Planning in Canada, and is overseen by a National Advance Care Planning Task Group comprised of individuals representing a spectrum of disciplines, including health care, law, ethics, research and national non-profit organisations.

## **What Is Needed In Australia**

Like all modern public health initiatives, the pursuit of death literacy and engagement programs in the community should seek to create social changes that promote healthy behaviours, reduce harm, and maximise well-being and quality of life.

Well considered public awareness campaigns coupled with implementation of advance care planning programs sponsored by collaborations between hospital and health services, PHNs and residential aged-care facilities will be needed in making system-wide change.

Because we live in a society that largely denies death or at least attempts to avoid it, and our reluctance to examine this experience shapes the way we view and think about dying well, Australians accept care at the end-of-life that often violates their own wishes.

Community awareness programs have the capacity to mobilise and maximise family, community, and workplace supports in an effort to reorganise a culture of denial toward a culture of acknowledgement of death as a natural part of life. We need to encourage the general public to talk more about death and dying or, more specifically, what they value the most to facilitate conversations and proper advance care planning processes.

The Institute for Healthcare Transformation at Deakin University seeks to transform end-of-life care through a conventional research and practice development program, as well as innovative

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<sup>29</sup> The Project on Death in America: twenty years on. Available online <http://endoflifestudies.academicblogs.co.uk/the-project-on-death-in-america-twenty-years-on/> (Accessed 7 July 2017)

healthcare professional-community awareness initiatives that help people have conversations about their end-of-life choices.

We can design, deliver and evaluate a well-considered and targeted public awareness campaign on advance care planning and end-of-life decision making, as part of an integrated suite of community behaviour change that would rival the effective safe driving campaigns, facilitate individual choice in end-of-life care and make system-wide advance care planning a reality.

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**RECOMMENDATION 2: Public Awareness Campaign**

**The Australian Government to fund or develop a well-considered and integrated public awareness campaign on death, dying and end-of-life conversations, as part of a suite of reforms, aimed at improving death literacy and facilitating community behaviour change.**

## **Omitted from box 4.8: Encouraging Talk about Death and Dying**

### **DeathOverDinner.org.au**

**DeathOverDinner** is an Australian public engagement campaign that advocates “dinner table” conversations with family and friends about wishes, values and preferences for healthcare.

It encourages people to have end-of-life conversations at the dinner table with family and friends rather than the ICU when it’s too late.

End-of-life care shouldn’t start with doctors, governments, insurance companies, or in intensive care units (ICUs) when people are overwhelmed; they should start with family and friends while breaking bread, and well in advance of an accident or an emergency.

**DeathOverDinner**, is an interactive website and cultural movement dedicated to giving people the permission and the tools to powerfully discuss their choices and thoughts on end-of-life with their friends and loved ones.

**DeathOverDinner**, in collaboration with Deakin University offers people the resources, tools and guidance to specifically gather individuals’ preferences for end-of-life care.

The campaign also casts a larger net, from a public health perspective. Social support has been shown to have the greatest influence on health- related quality of life outcomes. By gathering loved ones, friends, and people who matter most around the dinner table or a common meeting area, social engagement and support occur organically. These difficult discussions will become easier and more comfortable when taking place with important others, before a crisis, and in the comfort of a natural surrounding—not the intensive care unit.

### **Impact to date:**

- Important public awareness campaign
- Launched in Australia in mid-2016
- With minimal budget (<\$25,000)
- Within 8 months approximately 49,000 people had attended a Death Over Dinner in Australia
- Approximately 10% of all participants accessed a tool to complete a written advance care plan from a resource provided on the site (“My Values”, “Dying to Talk” etc.).
- Supported by the AMA and a range of community and medical leaders (see ambassador list in the slides).

See presentation attached

### 3. Funding Conversations

In Australia, there are significant time and financial disincentives for health professionals to have conversations with patients and deliver care that aligns with stated goals, values, and informed preferences. Published, peer-reviewed research shows that advance care conversations and planning lead to better care, higher patient and family satisfaction, fewer unwanted hospitalisations, and lower rates of caregiver distress, depression and lost productivity.

Adequate funding of these conversations deserves priority attention. Reimbursing these essential services would remove significant obstacles to making sure that people actually have conversations and receive advance care planning. It will also signal to clinicians that these conversations are valuable and will empower Australians to demand and expect this necessary, but often neglected, service.

There are several options for improving the efficiency and effectiveness of end-of-life care conversations and delivering more appropriate palliative care and end-of-life care services:

#### **A. Funding for General Practitioners (GPs)**

In Australia there is currently no dedicated Medicare Benefits Schedule (MBS) item for advance care conversations or planning. A series of non-specific item numbers are often muddled together. GPs play an important role in the care of patients as they approach the end of their life. Conversations and advance care planning requires commitment of time specific to that activity with the patient (30 - 90 minutes), with additional consults to review and update plans.

In the US, the value of advance care conversations and planning has been officially recognised and this represents a significant turning point for end-of-life care. From 1 January 2016, the Medicare physician fee schedule (covering up to US\$161.00) provides access to voluntary services and provides individuals with an important and often timely opportunity to establish their goals of care and preferences in the event of a serious illness. Focus now being placed on the next steps includes helping to ensure that advance care plans for all US patients are easily accessible and updated frequently, and that doctors are trained to have these difficult conversations.

Adopting a similar funding policy in Australia, and creating specific MBS item for end-of-life care conversations in Australia would make the provision of this important service more visible to GPs and enable greater promotion of the GP role and responsibility in advance care planning and management. This item number should include the development and review of advance care plans by GPs (of similar time and value to those Items for chronic disease management) as well as the ability to refer to allied health professionals subsidised by the MBS. This GP focus would also allow non-cancer patients to gain better access to services where discomforts may be more uncertain, particularly for disorders such as neurodegenerative disorders, congestive heart failure, liver disease, COPD or failed organ transplant, which are difficult to track and predict.

#### **B. Funding for Residential Aged Care**

Inadequate funding of “high care” patients in RACFs drives more people to inappropriately utilise acute, hospital and emergency services that are more expensive.

Patients treated in their homes / RACFs cost one-third the cost of a patient in an acute setting for end-of-life care. Rather than discourage RACF end-of-life care for high need patients we need to incentivise it and encourage innovation to better support these facilities to care for their residents until the end.

Ensuring GPs and palliative care nurse practitioners are reimbursed to provide care and have end-of-life conversations in the community is also critical. While there are existing items to support a home visit, there are no items relating to conversations and coordination of palliative care within a residential aged care facilities (RACF).

Reimbursement needs to consider the earnings lost from GPs not being available for consultations in their practice or to support GPs making visits to RACFs to have conversations, develop advance care plans and provide palliative care.

We promote the exploration of options for using the Aged Care Funding Instrument to have conversations and better achieve access to quality palliative and end-of-life care in RACFs.

The Commonwealth also needs to recognise the additional costs of rural and remote service provision, where financial and social welfare issues are more prevalent.

#### **C. Reimbursement for Family Conferences**

We lack MBS items that can facilitate health professional engagement with the families that could help health professionals better understand care needs, and help everyone agree on the goals of care for each patient. Funding of family meetings would reduce the time required when there are disagreements about the goals of care, and would potentially lead to a reduction in provision of futile and unnecessary care.

#### **D. Funding for Essential Services**

There are also a number of essential services that do not attract Medicare benefits, including issue of death certificates, cremation certificates and counselling of relatives. In addition, the federal government should require public reporting on quality measures, outcomes, and costs regarding end-of-life conversations for programs it funds or administers (e.g., Medicare, health insurance, the Department of Veterans Affairs [DVA], Centrelink and other social service benefits paid).

### **75-Plus Health Check**

We firmly believe it is too late to initiate an end-of-life care conversation at the 75-Plus health check.

Initiating end-of-life conversations earlier in a person's life cycle, at key maturation points, means the person is generally healthy and has decision-making capacity. This can normalise discussion about values and life goals that can be revisited overtime, as part of primary health care, or simply when having conversation within the family context during sentinel life events.

Ideally, these discussions would start early in adulthood, addressing global values and the selection of potential proxy decision-makers. With changes in health status, they would reflect more specific instructions.

No matter when conversations are initiated, all health professionals who have end-of-life care conversations are must have skills in end-of-life care and shared decision making.

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**RECOMMENDATION 3: Adequate Remuneration for End-of-life Conversations**

**The Australian Government to adequately remunerate GPs, RACFs and essential services to have end-of-life conversations to prevent unnecessary usage of emergency and acute care services. These conversations should be undertaken by competent and skilled professionals, at a time when the patient is ready (or on admission to a RACF) and earlier than the 75 plus health check.**

END

## Appendix Attachments

1. Bartel, R. (2016) Conversations: Creating Choice in End of Life Care. Melbourne: Australian Centre for Health Research (ACHR).
2. Death Over Dinner Presentation.